THE EFFECTS OF HOPE ON MENTAL HEALTH AND CHRONIC SORROW IN PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER

BY

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Abstract

This study examined the relationships among hope as defined by Snyder et al. (1991), a parents' hope for their child, autism severity, chronic sorrow, and mental health in parents of children diagnosed with an Autism Spectrum Disorder. The study yielded evidence of good internal consistency and validity for a new measurement of parents' hope for their child. Significant positive relationships were found between hope and parents' hope for their child, and between both types of hope and positive affect and satisfaction with support. Significant negative relationships were found between both forms of hope and autism severity, chronic sorrow, anxiety, and depression. The findings are interpreted as suggesting that hope and parents' hope for their child are important factors in positive coping in parents of children with autism. The representativeness of the sample is discussed as an important limitation of the current study.

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Thank you to my Mom and Geir for always being supportive and positive. Your pride and belief in me have helped me more than you can imagine. Thank you to my Dad for instilling in me an interest in knowledge and for inspiring me to always stretch a little bit further to reach my goals.

Most of all, abundant thanks to the three girls in my life. Elise Juniper Monsson, you are the smartest and funniest person I know. Never give up on your dreams and ,although I am sure

you never need to be reminded of this, only you can decide what goals you want to reach in life. Arlena Lily Ann Monsson, you are the light of my life and the best therapy for grouchiness and sadness. Christy Ann Monsson, I could not have done this without you and I feel your name should be right there next to mine on the diploma. Although we have gone through some hard times since autism became one of the most used words in our vocabulary, we have always come out stronger and closer. Your unwavering love has helped me through and given me strength when I was afraid I had none left.

Dedication

This project is dedicated to Arlena Lily Ann Monsson, my beautiful daughter. You are the purest and most honest person I know. Even though you are not able to talk, you show your love and affection for the people around you every day. You are the main inspiration for this project and I can truly say that it would not have happened without you. In this manuscript I write about how stressful and difficult it can be to be the parent of a child with autism, but there is also a wealth of happiness and love. I shed many tears after you were diagnosed and there are still some difficult days, but now most of my tears are tears of joy for all of the wonderful times you give me. For a long time I spent many hours every day wishing that you would be cured or that we would find the secret remedy for autism, until I realized that the only goal that really matters is that you have a good and happy life. You have made me a better and more hopeful person. Whenever I have a rough time now, I just picture your beautiful smile and remind myself of the delight with which you meet every new day. I am proud to be your father and I love you forever.

The Effects of Hope on Mental Health and Chronic Sorrow in Parents of Children with Autism Spectrum Disorder

Autism Spectrum Disorders (ASD), also referred to as Pervasive Developmental Disorders (PDD), cause severe and sustained impairments to affected individuals (NIMH, 2007). While there are some differences between the disorders in this group, all usually impair communication and social interaction, and produce problematic and non-functional behaviors (DSM-IV-TR, 2000). The impairments result in relentless stress on families, especially the parents or main caregivers. A number of studies have shown that parents of children with autism report higher levels of stress than parents of both typically developing children and children with other disabilities such as Down syndrome (e.g. Sanders & Morgan, 1997). These parents also score higher on measures of depression, anxiety, and grief, and lower on measures of marital satisfaction than the other parent groups (Hastings, 2003; Risdal & Singer, 2004).

Parenting a child with Autism Spectrum Disorder often lead to a condition referred to as chronic sorrow (Burke, Hainsworth, Eakes, & Lindgren, 1992). Parents feel an ongoing loss as a result of having a child that does not match their own or common expectations. This feeling of loss can lead to a long-term cyclical pattern of severe and milder periods of grief. While chronic sorrow and depression are found in many of the parents, some show better tolerance of the stressors. Social support, hardiness, optimism, and internal locus of control are some factors that have been found to positively affect the stress related mental health problems in these parents (Gill & Harris, 1991; Hassall, Rose, & McDonald, 2005; Higgins, Bailey, & Pearce, 2005).

Hope, as defined by Snyder and colleagues (Snyder, Harris et al., 1991), is a personality factor that has yet to be studied in this sample group. Higher levels of hope, however, have been found to relate positively with healthy functioning in other populations. Furthermore, Snyder

(2002) claimed that hope should serve as a defense against suffering and depression after experiencing loss. Thus hope could potentially be instrumental for healthier coping in parents of children with autism. The present study investigated the possible relationships among autism severity, hope, chronic sorrow and mental health in parents of a child with Autism Spectrum Disorder.

Autism Spectrum Disorders

Autism Spectrum Disorders (ASD) comprise five different disorders with important similar features: Autistic Disorder, Rett's Disorder, Childhood Disintegrative Disorder, Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). The main focus of the present study is parents of children diagnosed with either Autistic Disorder, Asperger's Disorder, or PDD-NOS. While Rett's Disorder and Childhood Disintegrative Disorder also are worthy of study, they have complicating features such as neurological impairments and more extensive loss of functioning than the other disorders, in addition to being less prevalent (DSM-IV-TR, 2000). This makes it difficult to perform an appropriate comparison.

Autistic disorder was first described by Kanner (1943) and is therefore often referred to as Kanner's autism. It is also sometimes labeled as Childhood Autism (WHO, 1993), classical autism or early infantile autism (Volkmar & Klin, 2005). Asperger's Disorder was described by Hans Asperger in 1944. Asperger's disorder is closely related to Autistic Disorder, with the main distinguishing feature being no significant delay in language and cognitive development before 3 years of age in Asperger's disorder. However, there is still much debate as to whether there is any actual difference between higher functioning Autistic Disorder and Asperger's Disorder (Volkmar & Klin, 2005). A diagnosis of Pervasive Developmental Disorder Not Otherwise

Specified (PDD-NOS) is given when the individual has severe impairments in social development and communication, or displays stereotypical behaviors or interests that don't meet the diagnostic criteria for Autistic Disorder or Asperger's Disorder (DSM-IV-TR, 2000). In this paper Autistic disorder, Asperger's Disorder, or PDD-NOS will be used when referring to the specific disorders, while autism or Autism Spectrum Disorders will be used to refer to the three disorders collectively. In general, most of the findings described herein are relevant to all three disorders. However, individuals with Autistic Disorder, or at least the majority of those diagnosed with this disorder, typically have more severe symptoms and lower functioning than those diagnosed with the other two disorders (Volkmar & Klin, 2005).

Autism has gained much attention the last few years following reports of an explosive increase in the prevalence of the disorder (NIMH, 2007). The rise in autism diagnoses is most likely due to better screening tools, more awareness of the disorders, changes in diagnostic criteria, and inclusion of Asperger's disorder and PDD-NOS in the ICD-10 (in 1992) and the DSM-IV (in 1994). The prevalence of Autism Spectrum Disorders is currently believed to be around 1 in 110 (CDC, 2009). The most recent epidemiological studies do not include a breakdown of the different disorders under the Autism Spectrum Disorder category, but previous studies have found that PDD-NOS is the most common of these disorders, followed by Autistic Disorder, and with Asperger's Disorder being the least widespread (Fombonne, 2005). There is also much debate regarding possible causes of autism, although most of the current evidence suggests a diathesis-stress causation (Kabot, Masi, & Segal, 2003). The symptoms and impairments displayed in autism appear to be related to widespread irregularities in brain anatomy and brain functioning due to abnormal brain development (Minshew, Sweeney, Bauman, & Webb, 2005).

While evidence points to autism resulting from neurological impairments, the diagnosis is still based on observable behavior traits. The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR, 2000) specifies that the individual must show impairments in social interaction and communication, and display restricted, repetitive behaviors, activities or interests to qualify for the diagnosis. For a diagnosis of Autistic Disorder the child must also display delays in social interaction, social communication, or symbolic play starting before three years of age.

One of the main features of autism is severe deficits in language and communication. Many children with Autistic Disorder never acquire functional language, with possibly as many as 50% remaining nonverbal throughout their lives (Bryson, Clark, & Smith, 1988). Others might only pick up a few words, while yet others might have a vocabulary that is close to normal for their age. It also has been found that some children with Autistic Disorder have seemingly normal language development until about 12 or 18 months, at which time they start losing the use of previously acquired words (Lord, Schulman, & DiLavore, 2004). While some children acquire language, they usually display abnormalities in its use. Echolalia is a common speech deviance in Autistic Disorder. Additionally, individuals with autism often display aberrant use of words, have problems with articulation and intonation, and have difficulties with the grammatical aspects of language (Tager-Flusberg, Paul, & Lord, 2005).

Another aspect of the communication impairments seen in individuals with autism is difficulty comprehending language and identifying the meaning in sentences or messages. This type of problem with comprehension also has been found in children that display near normal expressive language (Tager-Flusberg, 1981). Children with autism often are unable to understand irony (Happe, 1994) or other linguistic input where the intention of the speaker is not expressly

stated (Paul & Cohen, 1985). Moreover, such individuals show limited understanding of the non-verbal and social cues of communication, such as facial expressions and body language (Ozonoff, Pennington, & Rogers, 1990). Together, all of these factors make it difficult for anyone with an Autism Spectrum Disorder, and especially Autistic Disorder, to communicate effectively with people in their environment.

Impairments in communication turn out to be only part of a larger issue with social interaction in individuals with autism. From an early age people with Autistic Spectrum Disorders display dysfunctional social development. The first indication is usually a lack of eye contact, a symptom that often is seen throughout the lifetime of these individuals (Volkmar & Mayes, 1990). Children with autism will not attempt to share an object or event with another person, so called joint attention (Mundy, Sigman, & Kasari, 1990). Additionally, children with autism show deficits in imitation behaviors, one of the main avenues for early learning (Smith & Bryson, 1994).

Play, particularly symbolic, social and imaginative play, is another important forum for learning in normal children. These forms of play usually are absent or reduced in children with autism (Stone & Lemanek, 1990). Instead, children with autism show repetitive and nonfunctional manipulation of objects or parts of objects (Stone, Lemanek, Fishel, Fernandez, & Altemeier, 1990). In general, children with autism seem to lack interest in usual forms of play and they often fail to develop relationships with peers (Le Couteur et al., 1989). These missing social relationships and attempts at social interaction have been found to continue into adulthood (Orsmond, Krauss, & Seltzer, 2004).

While people with autism show interest in their environment, they often do not attend to the social aspects and, instead, focus on stimuli that are different from what is expected (Carter,

Davis, Klin, & Volkmar, 2005). Several hypotheses have been put forth to explain this abnormal social behavior. One claims individuals with autism view people in the same way they would any other object rather than as someone with whom to form a relationship (Klin, Jones, Schultz, & Volkmar, 2003). This hypothesis is supported by neurological findings that many people with autism do not process faces in the typical facial recognition areas of the brain (Pierce, Müller, Ambrose, Allen, & Courchesne, 2001). Another hypothesis is that the social difficulties in autism result from lacking a "Theory of Mind", or ability to understand the viewpoint, thoughts and feelings of others (Baron-Cohen, 1995).

Individuals with autism also display abnormal behavior patterns in other areas. One of the main diagnostic features of the disorder is the presence of repetitive, ritualistic and stereotyped behaviors, interests and activities (DSM-IV-TR, 2000). Stereotyped and repetitive behaviors include rocking, handflapping, mouthing, vocalizing, staring at lights, and touching different surfaces (Turner, 1999). Many of these behaviors appear to be performed solely for the stimulation they provide (Militerni, Bravaccio, Falco, Fico, & Palermo, 2002) and are therefore sometimes referred to as self-stimulatory behaviors (Dunlap, Dyer, & Koegel, 1983). With increased intelligence and development it is also common to see stereotyped ritualistic behaviors such as lining up things, hand washing and repeating sequences of behaviors (Loveland & Tunali-Kotoski, 2005). Some of these rituals appear similar to those found in Obsessive Compulsive Disorder, but usually are less complex and organized (Swedo & Rapoport, 1989). Limited and stereotyped interests often are found in people with autism, and are especially prevalent in individuals with Asperger's Disorder (Loveland & Tunali-Kotoski, 2005). Stereotypy in autism can also be seen in a rigid need to follow routines. Many individuals with

autism react negatively to changes in routines or schedules, something that can cause difficulties at home and school (Norton & Drew, 1994).

One of the most severe and problematic stereotypical behaviors in individuals with autism, especially Autistic disorder, is self-injurious behavior. Some of the most common self-injurious behaviors are head banging, head hitting, eye poking, self-biting and self-scratching (Berkson, Tupa, & Sherman, 2001). These behaviors can be so severe that they cause permanent damage, and they often have a strong emotional impact on others. Although many of these behaviors are performed for the stimulation, they can also be used to create responses from the environment (Dunlap & Fox, 1996).

Unfortunately individuals with autism also display high rates of destructive and disruptive behaviors toward people and things. These aggressive and disturbing behaviors can include kicking, biting, yelling, throwing objects, destroying property, playing with feces, and removing clothes at inappropriate times (Matson & Rivet, 2008). The behaviors might be attempts at communicating needs to the environment or be the result of frustration or strong emotions (McKlintock, Hall, & Oliver, 2003). Such behaviors are harmful due to the negative reactions they elicit and because they can hinder learning and socialization (Matson & Nebel-Schwalm, 2007).

As mentioned above many stereotypical behaviors appear to be performed to create sensations, but other abnormalities also are related to sensory input. Many seem to find certain sensations aversive or even painful. Such sensations can include touching specific textures, tasting food with a particular texture or consistency, seeing certain things or hearing certain sounds (O'Neill & Jones, 1997). It has been hypothesized that this type of hyper-sensitivity may be a factor in aberrant attachment and social learning (Talay-Ongan & Wood, 2000).

Hyper-sensitivity to certain textures, when combined with cognitive and emotional factors, can result in low levels of food acceptance for many individuals with autism (Ahearn, Castine, Nault, & Green, 2001; Ledford & Gast, 2006). It is also common to find other dieting issues such as obsessive eating habits, gorging and pica (Collins, et al., 2003; Kerwin, Eicher, & Gelsinger, 2005). Additionally, individuals with autism often have such gastrointestinal issues as vomiting, diarrhea, constipation, and gastroesophageal reflux (Horvath, Papadimitriou, Rabsztyn, Drachenberg, & Tildon, 1999; Mason-Brothers et al., 1993). A study of eighty-nine children with pervasive developmental disorders found a significant relationship between gastrointestinal symptoms and self-injurious behavior, suggesting the behaviors may be the result of gastrointestinal pain or discomfort (Kerwin et al., 2005).

An abnormal sleep pattern is another problem often noted in individuals with autism. The sleep problems can be severe and include shortened night sleep, early morning awakening, prolonged sleep latency, and nighttime awakening (Honomichl, Goodlin-Jones, Burnham, Gaylor, & Anders, 2002; Schreck & Mulick, 2000). Studies also have shown that many people with autism have abnormal REM sleep (Thirumalai, Shubin, & Robinson, 2002). Together these factors lead to less sleep and lower sleep quality (Elia et al., 2000). Additionally, children with autism often display rigidity related to bedtime and sleep routines. While this is part of their larger problem with stereotypy, it can tend to have a negative effect on their own and their family's sleep patterns (Patzold, Richdale, & Tongue, 1998).

Autism Spectrum Disorders have been found to be highly correlated with a number of other disorders and medical conditions. Seizures and epilepsy have been reported in as many as one third of individuals with autism (Rossi et al., 1995; Tuchman & Rapin, 2002). The appearance of seizures can lead to further cognitive impairments and has been found to be one of

the main causes for higher mortality rates in people with autism (Aarts, Binnie, Smit, & Wilkins, 1984; Nordin & Gillberg, 1998; Shavelle, Strauss, & Pickett, 2001).

Motor problems and delayed motor development are common symptoms in children with autism (Baranek, Parham, & Bodfish, 2005). These children often are found to have poor coordination and deficits in visual-motor skills (Gilberg, 1990). Some of the motor difficulties are likely related to impairments in the ability to imitate (Stone, Ousley, & Littleford, 1997). The motor problems are revealed by the presence of involuntary movements in a subgroup of individuals with autism (Leary & Hill, 1996). Motor difficulties can make it harder for some children with autism to engage in common activities and set them further apart from their peers.

The prevalence of mental retardation in autism is high, with some estimates at 70% to 80% (Tager-Flusberg, Joseph, & Folstein, 2001). However, there are large differences in the rates among the different disorders on the spectrum, with low rates in Asperger's Disorder and PDD-NOS, and high rates in Autistic Disorder (Shea & Mesibov, 2005). The prevalence of mental retardation is lower in younger cohorts of individuals with autism than in older individuals, most likely due to improved knowledge, interventions and treatment (Eaves & Ho, 1996). The presence of mental retardation is usually associated with a more negative prognosis and significant dependence, even into adulthood (Howlin, Goode, Hutton, & Rutter, 2004).

Effects of Autism Spectrum Disorders on Parents

As described above, individuals with Autism Spectrum Disorders have many pervasive and severe symptoms. Being the parent of such a child will therefore lead to a number of stressors not experienced by parents of typical children. Studies have found that parents of children with autism report higher levels of emotional and physical stress than parents of normal children (Yamada et al., 2007) and also more stress than parents of children with other disorders

such as Down syndrome (Pisula, 2007; Sanders & Morgan, 1997), cystic fibrosis (Bouma & Schweitzer, 1990), and fragile X syndrome (Abbeduto et al., 2004). The additional stress leads to increased rates of depression, anxiety and mental health problems among parents of children with autism (Bitsika & Sharpley, 2004; Hastings, 2003; Sharpley & Bitsika, 1997).

Parents report a sense of shock from receiving the diagnosis for their child, even when the symptoms of the disorder are quite obvious (Fleischmann, 2004; Hutton & Caron, 2005). In one study parents expressed that when they received the diagnosis "their 'quality worlds' collapse" (Trigonaki, 2002, p. 13). For these parents the diagnosis signifies the end of the plans and future goals they had for their children, and their view of the world is forever altered. The adjustment to the new situation and possible future is complicated by the uncertainty of the prognosis. Because the developmental trajectory of children with autism is uneven and unusual it is difficult for parents to know what to expect in the future (Marcus, Kunce, & Schopler, 2005).

In general, the severity of the child's symptoms is positively correlated with the stress parents experience (Tomanik, Harris, & Hawkins, 2004). Impairments in language and communication have a particularly strong effect on the mental health of parents (Konstantareas & Homatidis, 1989). Communication difficulties have a negative effect on the attachment between parent and child (Ello & Donovan, 2005). This is especially the case when language deficits are paired with such common symptoms of autism as withdrawal from the environment or lack of interest in social interactions (Duarte, Bordin, Yazigi, & Mooney, 2005). Inability to communicate with language makes it more difficult for parents to regulate and reinforce their child's behaviors (Ello & Donovan, 2005). Language impairments also have a negative effect on learning and have been found to be a strong negative predictor of future functioning (Tager-Flusberg et al., 2005).

Having a child with an Autism Spectrum Disorder will, in almost every case, signify increased caretaking responsibilities. Most individuals with autism require support throughout their lives, and some low functioning individuals might be permanently dependent on their parents for assistance with every aspect of their existence. This caretaking responsibility has been found to add emotional and physical stress to parents (Koegel et al., 1992; Rodrigue, Morgan, & Geffken, 1990). The type of care the child needs also has a strong effect on parents' stress. Individuals who are unable to acquire important self-help skills and who continue to require help with such tasks as toileting, feeding, and grooming are the largest burden for caretakers (Plant & Sanders, 2007). In some cases parents are left with no option other than to place their child in a residential care facility. While this might ease the physical burden, it has been found that guilt and longing for their child adds stress to many parents (Benderix, Nordström, & Sivberg, 2006).

While fathers might be more involved in raising children today than previously, the majority of caretaking still falls on the mother. This increased caretaking responsibility has been found to be a main reason for higher levels of stress, depression and anxiety in mothers as compared to fathers (Moes, Koegel, Schreibman, & Loos, 1992). Many mothers give up their career to take care of the child. This can be a great disappointment and it also means that they have fewer opportunities to socialize. Additionally, they will have less time than fathers to escape from the stressors of the home (Gray, 2003).

Although not widespread, it is not uncommon for a family with a child with autism to have an additional child with autism or another disability. Due to a possible genetic link in Autism Spectrum Disorders, couples who already have a child in the spectrum of disorders have an increased likelihood of having another child with autism. Bolton and colleagues (1994) found

that the rate of autism in siblings of individuals with autism was 3%, with an additional 3% showing a more broadly defined Autism Spectrum Disorder. Having a child with autism also might increase the likelihood of having a child with another type of cognitive deficit or mental retardation, with as much as 13 to 17% of siblings of individuals with autism showing such impairments (August, Stewart, & Tsai, 1981; Boutin et al., 1997). Having several children with disabilities increases the caretaking responsibility and also the emotional impact, and it has been found that parents with more than one child with a disability often experience more stress and depression than parents with one child with autism (Orsmond, Lin, & Seltzer, 2007).

Children with autism also require increased work outside of the home. While it might seem that school and professional help would ease the stress parents experience, dealing with school and other care providers actually is a major source of stress (Redmond & Richardson, 2003). Many parents report that they have to fight to acquire adequate services for their child and many feel the support they receive is not sufficient for the child to reach their potential (Marcus et al., 2005). In a study of eighty-three parents of children with disabilities parents felt the people providing the services were insensitive to their needs and feelings (Knox, Parmenter, Atkinson, & Yazbeck, 2000). Some parents also experience stress related to the large number of care providers working with their child. This makes it difficult to feel in control of the services and it also creates insecurity regarding their own role as a caregiver (Smith & Antolovich, 2000).

Finding the best services and treatments for the child can also be a source of stress (Marcus et al., 2005). The market is flooded with different treatments and providers trying to push their interventions. While scientific research shows that behavioral treatments yield the best results, many other treatments make similar claims, making it difficult to know what is accurate (Green, 1996). Additionally, there are a number of different theories about the causes of autism,

each with its own treatment. Parents might be uncertain about the right course of treatment, and they also experience guilt for possibly not providing the treatment that might "cure" their child (Marcus et al., 2005).

While most of the different treatments will not harm the child, they can add to the family's financial burden. Treatments and services are expensive, and school districts and states usually do not provide enough support, meaning that the family must pay for additional services from their own budget. In a study of 55 parents of children with autism, more than half reported spending more than $6,000 per year in support services or treatments (Twoy, Connolly, & Novak, 2007). These expenses, together with other common expenses related to children with autism (e.g., special diets, diapers, safety measures for the home, special toys) put a heavy financial burden on the family (Baldwin, 1985). The monetary situation is even more stressful for families where the mother stays home to take care of the child (Shearn, 1998; Shearn & Todd, 1997).

Parents of children with autism experience difficulties in most social environments. Children with autism display such aberrant and socially unacceptable behaviors as inappropriate crying, shouting and tantruming (Konstantareas, 1991). In a study of 219 parents of children with autism, lacking acceptance and understanding from people in their environment was identified as one of the main stress factors (Sharpley & Bitsika, 1997). Many parents indicate that their child's normal physical appearance makes it harder for people to understand the abnormal behavior, and that they often are met with insensitive reactions and remarks (Sander & Morgan, 1997). Some feel their child is rejected and discriminated against by society (Schall, 2000).

Problem behaviors, including self-injurious and aggressive behaviors, are a significant source of stress for parents of children with autism (Bishop, Richler, Cain, & Lord, 2007;

Bromley, Hare, Davison, & Emerson, 2004; Hastings, Daley, Burns, & Beck, 2006). Some studies have shown that such behaviors predict stress and depression more strongly than does the cognitive functioning of the child (Baker, Blacher, Crnic, & Edelbrock, 2002; Beck, Hastings, Daley, & Stevenson, 2004). Problem behaviors lead to additional exertion and responsibility for parents both at home and in the social environment (Lecavalier, Leone, & Wiltz, 2006). In one study, parents perceived their children as less attractive, appropriate, and intelligent when they had behavior problems (Noh, Dumas, Wolf, & Fisman, 1989). It is likely that people in the social environment have similar reactions.

Many parents have concerns about the safety of the child when the child is away from home (Hutton & Caron, 2005). While safety can be a cause of stress at home too, parents usually are able to regulate and put safety measures in place in the home. These things usually are not available outside of the home, and people in the environment might be unaware of the child's safety needs. Additionally, due to their social understanding deficits and limited communication skills, individuals with autism may be at heightened risk for exploitation by others (Shea & Mesibov, 2005).

Problem behaviors, safety issues, and rejection often cause parents to be overprotective of children with autism (Pisula, 2007). Many parents report that they choose isolation rather than struggling with the stress of bringing their child into the social environment (Emerson, 2003; Sanders & Morgan, 1997). Unfortunately, such isolation can exacerbate the emotional impact on parents as they have fewer outlets for stress (Gray & Holden, 1992). Additionally, lack of socialization can further impair the child's social development (Loveland & Tunali-Kotoski, 2005).

As mentioned above, children with autism often have abnormal sleep patterns that negatively affect the sleep of their parents. In a study of thirty-five mothers and twenty-two fathers of children with autism, Meltzer (2008) found that these parents had fewer hours of sleep, more interruptions in their sleep and poorer sleep quality than parents of typically developing children. In the short-run, deficient sleep can lead to reduced energy and ability to face stressors. In the long-run, sleep deficits can lead to Chronic Partial Sleep Deprivation (CPSD), which is characterized by fatigue, elevated stress, and negative mood (Dinges, Rogers, & Baynard, 2005).

The physical and emotional stress of raising a child with autism can cause exhaustion. Several studies (Sen & Yurtsever, 2007; Risdal & Singer, 2004) have found that this can have a negative impact on marital adjustment and marital quality, possibly leading to higher rates of divorce in parents of children with autism. Marriages also can be negatively affected by time constraints due to caregiver responsibility. Parents have little time to spend by themselves or with each other, deteriorating the quality of their life and marriage (Hutton & Caron, 2005). Marital problems can, in turn, increase the amount of stress on the family (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006).

In addition to increased rates of depression and anxiety, parents report feelings such as failure, guilt, anger, and helplessness as a result of the stress of taking care of a child with autism (Higgins, Bailey, & Pearce, 2005; Sen & Yurtsever, 2007). Many parents also report feeling grief and sorrow (Tunali & Power, 2002). These emotional reactions have been described in the literature on chronic sorrow, a factor that will be investigated in the current study. A closer description of this theory is therefore provided next.

Chronic Sorrow

The concept of chronic sorrow was first proposed by Olshansky (1962) during the course of his work with children with intellectual disabilities and their parents and family members. Olshansky observed that the parents of these children displayed "…a pervasive psychological reaction" to the experience of having a "…mentally defective child" (p.190). The psychological reaction was a type of grief similar to that found in parents who have lost a child. However, the parents of a child with mental retardation experienced chronic sorrow as the loss they were feeling was ongoing rather than time limited. The length of the loss was also uncertain, ending either with the death of the parent or the child. While parents were affected by their grief, they were not incapacitated by it because their caregiver role would not have allowed such a reaction. Olshansky did not expand on the chronic sorrow concept. His main concern was to create awareness of the phenomenon and to emphasize that the grief was a natural rather than neurotic reaction.

Since Olshansky (1962) first introduced the chronic sorrow concept, researchers have developed the theory to offer a more detailed explanation of the loss and grief. The felt loss that leads to chronic sorrow came to be viewed as different from bereavement because the loss can never be resolved. That is, the person who is lost in the context of profound cognitive impairment is still physically present although not fully present in a relational context. Because the person is not lost in a physical sense it is a symbolic rather than an actual death (Teel, 1991). The loss is experienced as what "used-to-be" but is no longer or, in relation to children with autism, as the loss of the "ideal" or "expected" child. A child with autism might have been abnormal from birth, but they still may be grieved because the parent is experiencing the loss of dreams, hopes, and expectations that were held before the child was born (Roos, 2002).

Autism Spectrum disorders create a disparity between the individual as they are and how they were expected to be. It is this disparity or, more specifically, the interpretation of such a disparity, that is experienced as a loss (Ahlstrom, 2006). Teel (1991) specified that the disparity would only lead to strong grief reactions when it affects strong attachment relationships such as those between a parent and a child.

The loss experienced by people in these situations is ongoing. While death is a singular and final event, the symbolic death that causes chronic sorrow is continuous as the individual is still physically present. Parents of children with developmental disabilities also experience a series of losses. This is because the child, while not necessarily losing functional capacities, falls further and further behind typically developing same-age peers. Parents of such children experience a loss with every milestone the child does not attain (Eakes, Burke, & Hainsworth, 1998).

The effect of the ongoing loss is magnified by uncertainty for the future. With many disorders there is not a predictable end, and while death is the final outcome for many of these disorders, the road and the losses leading up to this point are usually ambiguous. For Autism Spectrum Disorders there is great uncertainty related to the diagnosis and prognosis and it is usually difficult to predict how high-functioning the individual will be (Marcus et al., 2005). This uncertainty will often increase the grief reaction as people experience a feeling of loss of control over their futures (Roos, 2002). This loss of control is magnified in parents who are presented with ever increasing caretaking responsibilities. They have to continually redefine their lives as the disorder progresses or as the affected child approaches physical maturity (Hodder, 2006).

While chronic sorrow is ongoing and long-term, it is experienced as a periodic or cyclical phenomenon, with periods of intense grief interspersed with periods of less intense grief or even positive mood (Kearney & Griffin, 2001; Wikler, Wasow, & Hatfield, 1981). During the intense periods the individual might experience sorrow that is just as strong as when the child was diagnosed. Senour (1981) labeled these periods of intense grief "islands of sorrow" (p.390). In grief reactions after a death, there might also be recurring episodes of sadness. However, these usually decrease in severity over time (Heikkinen, 1981). This is not seen in chronic sorrow because the loss is ongoing. In some cases the buildup effect of numerous losses results in an intensifying of grief over time (Lindgren, Burke, Hainsworth, & Eakes, 1992).

The periods of intense sorrow are triggered by internal or external factors that remind the person of the loss (Lindgren et al., 1992). An external factor for the parent of a child with autism could be observing the actions of typically developing children of the same age. Internal factors are thoughts and emotions that bring the loss to the forefront, such as thinking about how a child may never marry or have children. Burke, Eakes, and Hainsworth (1999) labeled the triggers of the grief episodes milestones. Through interviews with 98 individuals experiencing chronic sorrow, the authors identified several typical milestones: Comparisons with social, developmental, or personal norms; management crises; anniversaries; memories; unending care giving; and role changes were mentioned as the most common triggers of grief episodes.

Chronic sorrow, then, represents a "recurring, periodic sadness that is permanent and progressive" (Lindgren et al., 1992, p.30). Copley and Bodensteiner (1987) proposed a two-phase model for the development of periods of chronic sorrow. The first phase starts after the diagnosis or the realization that the child has autism. This phase is characterized by cycles of impact, denial, and grief. During this phase parents experience high peaks and valleys of emotion

as they attempt to cope and adjust to the loss (Krafft & Krafft, 1998). Most parents are unable to progress beyond this first phase and continue to cycle through phases of impact, denial, and grief. Those who do make it through the first phase move into a second phase where the focus turns outward and they may find a sense of closure (Teel, 1991, p.1315). Closure here is not necessarily the same as acceptance of the loss, but rather the ability to live with and adjust to the effects of the loss on daily life. Parents in this phase find new meaning in their situation by finding positive aspects in their life and their child and by formulating new goals to work toward, such as advocating for their child or all individuals with autism. While the grief is never fully resolved, it is less intense and frequent in the second phase (Copley & Bodensteiner, 1987). Teel (1991) warned that denial of the loss specified in the first phase of this model has not generally been considered a part of chronic sorrow, but that denial of the chronic sorrow experience itself is a more likely reaction.

Lindgren et al. (1992) claim that, while chronic sorrow is related to depression, the two states are different. Chronic sorrow is always set off by a loss. This usually is not the case with depression (Burgess, 1990). Depression is characterized by a personal focus with reduced self-efficacy and feelings of emptiness. This is different from chronic sorrow where the emptiness and loss are focused on another person (Osterweis, Solomon, & Green, 1984). Depression is also often found to be a debilitating condition. In contrast, chronic sorrow does not inhibit daily functioning (Lindgren et al., 1992). Depression is defined as a mood disorder with longer periods of depressed mood. While parents experiencing chronic sorrow have periods of more severe sadness, these usually are not as long-lasting or as encompassing. Chronic sorrow is more cyclical than depression, and the severe periods are always set off by internal or external

milestones (Lindgren et al., 1992). However, many parents of children with autism experience both chronic sorrow and depression (Burke, 1989).

The Effects of Coping Mechanisms on Stress and Mental Health

As discussed above, the severe and pervasive symptoms displayed by individuals with Autism Spectrum Disorders add many stressors to their parents' lives. These stressors can lead to such reactions as depression, anxiety and chronic sorrow. However, while most parents of children with autism will report some of these reactions, some parents cope well with the additional stress in their lives (Hastings et al., 2005; Summers, Behr, & Turnbull, 1988). Research has shown that different personality factors and coping mechanisms are effective barriers against the stressors and negative reactions experienced by parents of children on the autism spectrum.

Social support is important for most humans, and studies have shown that such support is even more essential when facing the challenges of raising a child with autism. Many parents of children with autism point to support from family and friends as one of the most important factors for positive coping (Smith, Oliver, & Innocenti, 2001; Twoy et al., 2007). Family members often provide help with caretaking and easing the financial burden, and they also provide emotional support. This is one of the reasons informal support has a larger effect on parents' well-being than help from such formal sources as teachers and therapists (White & Hastings, 2004). While some studies indicate that having a child with autism decreases family adjustment and the quality of family interaction, there are also studies showing the opposite effect, with family members reporting their family as more connected, resilient and supportive as a result of having a child with Autism Spectrum Disorder (Bayat, 2007). This effect also has been reported in several studies on marital quality in parents of children with autism. Although

the incidence of divorce might increase, many couples express that their relationship became stronger and that the support from their partner is one of the main reasons for their positive coping (Higgins et al., 2005; Kersh, Hedvat, Hauser-Cram, & Warfield, 2006). Parents report that their spouse and family serve as buffers against stress (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001) and help them stay hopeful (Siklos & Kerns, 2006).

Seeking strength through faith or religion is a coping strategy that can reduce stress and depression for some parents (Tarakeshwar & Pargament, 2001). In a study of fifty-five parents of children with autism, almost half stated that they had faith in God and used religion as a source of coping (Twoy et al., 2007). However, a study by Hastings et al. (2005) found that relying too much on religion for coping could have negative effects. In this study, individuals using religious coping as their main strategy had higher ratings of depression and stress than parents who used other strategies. The authors hypothesized that denial is a main factor in religious coping and that this may impair efforts to find more positive aspects in the situation.

In the same study (Hastings et al., 2005), people who used problem solving and positive coping strategies were found to have reduced rates of depression, anxiety and stress. Problem solving involved taking action to make the situation better, working out strategies for how to change the situation, and pursuing other active change strategies. Positive coping included finding something good or positive in the situation, trying to see the situation in a new and more positive light, and learning to live with the situation. These strategies involve attempts at change, problem solving through actual attempts at changing the situation and positive coping through changing the perception of the situation. The results also fit with the two-phase model for chronic sorrow, where parents are hypothesized to move into the second and more positive phase

by finding new goals and changing the way they view their world (Copley & Bodensteiner, 1987).

The positive effects of reframing or redefining perceptions of negative outcomes have been found in several studies (e.g. Luther, Canham, & Cureton, 2005). In a study by Glidden, Billings, & Jobe (2006) positive reappraisal was found to be particularly effective, and healthier than coping strategies such as escape-avoidance, confrontive coping, planful problem solving and distancing. These authors defined positive reappraisal as positively interpreting "events in order to achieve personal resolution and growth" (p. 958). The authors claim this strategy is effective because the parents of children with autism are in a situation that cannot be changed; they can only change the way they view the situation. A study of 103 families of children with pervasive developmental disorders (Trute, Hiebert-Murphy, & Levine, 2007), found that the families were better adjusted when parents used positive appraisal as a coping mechanism. Parents who used positive appraisal were able to view their problems as challenges rather than stressors and they also had a more positive view of their child. Most studies show that coping strategies involving denial are ineffective (Bayat, 2007; Dunn et al., 2001; Lloyd, & Hastings, 2008). When parents use reframing they do not deny the problems, they acknowledge the stressors and find life satisfaction through alternative goals and other ways of achieving goals (Tunali & Power, 2002). Many of these parents report that they become more aware of and derive more pleasure from their child's progress, however small (Bayat, 2007).

Reframing also is found to be an important factor in what Antonovsky (1987) labels Sense of Coherence (SOC). SOC is defined as:

> "a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (1) the stimuli deriving from one's internal

> and external environments in the course of living are structured, predictable and explicable; (2) the resources are available to one to meet the demands posed by these stimuli; and (3) these demands are challenges worthy of investment and engagement" (Antonovsky, 1987, p.19).

People with a strong SOC feel that they can comprehend their environment, that they are able to manage the demands from the environment, and that it is worthwhile to attempt to deal with these demands. These individuals should be better able to deal with stressful events because they view stressors as challenges rather than solely negative factors. A study of 216 families with a member with autism (Olsson & Hwang, 2002) found that while parents of children with autism were more likely to be depressed than parents of children without autism, none of the parents of children with autism who were high in SOC scored in the depressed range on Beck's Depression Inventory (BDI). The authors hypothesized that high SOC works as a buffer against stress because high SOC people are able to redefine their goals. People who are low in SOC, on the other hand, use their energy on emotion regulation, an ineffective strategy in the long term because it does not alter either the situation or the individual's perspective.

In a study of 155 mothers with a child with autism (Mak, Ho, & Law, 2007), SOC acted as a moderating variable between level of severity of symptoms and perceived stress. While low SOC mothers reported increased stress as their child's symptoms increased, this effect was not observed in high SOC mothers. The authors also found that high SOC mothers reported less stress in general. The high SOC mothers were more confident of their parenting abilities and they also expressed more acceptance of their child.

Self-efficacy is a personality factor that is closely related to Sense of Coherence. Bandura (1977) defined self-efficacy as a person's perception of their ability to cope with specific

situations, or their belief that they can perform in a certain way to achieve specific goals. While people have an overall self-efficacy, they also have self-efficacy related to specific domains. In a study of twenty-six mothers and twenty fathers of children with autism, Hastings and Brown (2002) found that self-efficacy was a mediator between level of problem behavior and stress in mothers, while it worked as a moderator for the same relationship in fathers. In both cases parents high in self-efficacy reported less stress resulting from the problem behaviors. Kuhn and Carter (2006) investigated self-efficacy related to parenting in 170 mothers of children with autism. Self-efficacy was again positively related to well-being. Mothers high in maternal self-efficacy expressed more belief in themselves and in their parenting skills. The same study found that maternal agency was a significant predictor of self-efficacy. Maternal agency was described as the mother's taking an active role in parenting and engaging with the child. Maternal agency also had a significant inverse relationship with feelings of guilt, with mothers high in maternal agency reporting lower levels of guilt than those with low maternal agency.

Hardiness is another personality attribute that has been shown to have a positive influence on coping. Hardiness is defined by Salvatore Maddi (Kobasa, Maddi, Kahn, 1982) as a personality characteristic consisting of commitment, control, and challenge. Commitment involves a tendency to involve oneself in situations rather than to alienate oneself from them. Control involves perceiving that one has the resources, knowledge and skills to deal with life stressors. Challenge involves a belief that change is normal and a source of growth rather than a source of threat. Hardy people have been found to embrace stressors and to view them more as positive factors in life. These people are therefore better able to handle stress and have been found to report greater well-being (Kobasa, 1979).

Gill and Harris (1991) studied the effect of hardiness on coping in sixty mothers with children with autism. Hardy mothers reported fewer depressive symptoms and somatic complaints than their low hardiness counterparts. Hardy mothers also reported being better able to deal with the stressors arising from raising a child with a disability. Hardiness was a stronger predictor of well-being than social support.

Studies of locus of control reveal that this also can be an important factor in the experience of stress. Rotter (1966) proposed that people either have an external or internal locus of control. Those with an internal locus of control believe that they can control the outcomes of situations. Those with an external locus of control believe that outcomes are controlled by external forces. In a study of 39 mothers and nineteen fathers of children with autism (Dunn et al., 2001), parents with an external locus of control reported more stress than those with an internal locus of control. External locus of control parents were also more likely to feel socially isolated. Similar results were found in a study of mothers of children with intellectual disabilities (Hassall, Rose, & McDonald, 2005). Internal locus-of-control mothers experienced less stress and had higher self-esteem. These studies demonstrate that believing that you can influence your situation is important for coping.

Optimism as defined by Scheier and Carver (1985) has also been related to coping by parents of children with autism. Optimists "expect things to go their way, and generally believe that good rather than bad things will happen to them" while pessimists expect "things not to go their way, and tend to anticipate bad outcomes" (p.219). Baker, Blacher and Olsson (2005) found that optimistic parents (as measured by the Life Orientation Test, LOT; Scheier, Carver, & Bridges, 1994) reported greater well-being than those who were more pessimistic. Optimism also moderated the relationship between behavior problems displayed by the child and the parents'

perceived stress, with the behavior problems having less negative effect on optimists than pessimists. In general, parental optimism had a stronger effect than childrens' problem behaviors on parents' well-being. This relationship between well being and optimism was also found in a study of 102 mothers caring for a child with autism (Greenberg, Seltzer, Krauss, Chou, & Hong, 2004). Optimistic mothers also perceived their physical health and their relationship with their children more positively.

Hope Theory

Hope is a personality factor that has been found to be important for coping in general, but it has yet to be studied in parents of children with autism. Snyder, Irving, and Anderson (1991) defined hope as "a positive motivational state that is based on an interactively derived sense of successful (a) agency (goal-directed energy), and (b) pathways (planning to meet goals)" (p. 287). Hope is a cognitive set involving interaction between pathways and agency thinking directed toward desired goals. Individuals believing that they can create the pathways or routes to reach their goals (pathways thinking), along with the motivation to use these pathways (agency thinking), are thought of as hopeful. High-hope individuals, therefore, believe they have both the means and motivation to reach desired goals (Snyder, 2000a).

Goals

Hope theory claims that all human behavior is goal directed. Goals can be big or small, can be short-term or long-term, and can be either clearly or only vaguely conceived. Clear goals hypothetically facilitate pathways thinking as compared to vague goals where even the wanted end state may be unclear. Different goals also may have different values to the person pursuing them, with high-value goals theoretically creating more agency thinking than low-value goals. A

goal must pass a certain value level before the person will invest effort in pursuing it (Snyder, 1994).

Snyder (2002) also distinguished between "approach" and "avoidance" goals. As the names suggest, approach goals involve achieving positive outcomes, whereas avoidance goals entail preventing negative outcomes. Both types can inspire agency and pathways thinking, but approach goals are thought to lead to more energetic efforts. Additionally, selecting one type of goal may leave less energy available to pursue others (e.g. selecting many avoidance goals may leave little energy available for approach goals).

Theoretically, people have goals for most aspects or domains of life, but they have more goals, and agency, for domains that are considered important. The importance that is placed on the different domains will help guide goal selection in many situations (Snyder 1994).

Pathways

Within Hope theory, pathways thinking reflects the perceived capacity to generate routes to reach goals. Several pathways may be imagined for a specific goal, but a person typically will pursue only one primary pathway. If the chosen pathway is blocked or unsuccessful, the individual may pursue alternative pathways. As with goals, pathways can be vague or specific, with specific pathways having a higher likelihood of leading to success. Snyder (2002) theorized that pathways also are refined and made more specific as the person moves closer to a goal. High-hope individuals are more confident and adept at creating pathways than are their low-hope counterparts (Yoshinobu, 1989). When encountering goal blockages, high-hope persons should usually be more successful than low-hope persons because they are more facile at generating and implementing new pathways (Snyder, Lehman, Kluck, & Monsson, 2006).

Agency

According to Snyder and his associates (Snyder, Harris et al., 1991) agency thinking is the perceived capacity to find the motivation to use pathways to reach desired goals. Such thinking is influenced both by the belief that a pathway will work and the belief that one will be able to complete the pathway. If a person has little faith in a successful goal pursuit, the odds of mustering or sustaining the required energy are reduced. Agency, then, is not only the motivation to start along a pathway, but also to continue along it once movement is initiated. Theoretically, high-hope people typically have the needed agency or motivation to succeed in their goal pursuits. Successfully reaching a goal, in turn, provides feedback about what types of pathways are effective, and also boosts agency thinking by increasing the belief in future achievements. Theoretically, agency is crucial when a pathway has been blocked because it provides the motivation to create or pursue alternative pathways (Snyder, 2002).

High Hope vs. Low Hope

Hope can be both a state and a trait, with trait hope representing the person's long-term level of hope, and state hope reflecting a more short-term form of hope that is influenced by both trait hope and "here-and-now" situational factors. The Snyder Hope Scale (HS-R2; Shorey, et al., in press), a revised version of the Trait Hope Scale (Snyder, Harris, et al., 1991), was developed specifically to assess trait hope. The scale measures levels of pathways thinking, agency thinking, goals thinking, and overall hope. Although it is possible to have any combination of scores on the subscales, a person who is high in hope typically will have high levels on all scales, whereas a low-hope person will tend to have low scores.

High-hope persons are theorized to approach goals differently from their low-hope counterparts (Snyder, Harris, et al., 1991). High-hopers tend to pursue their goals more actively

and to select goals that require reasonable efforts to achieve (Harris, 1988). Theoretically, by selecting such "stretch" goals those persons who are high in hope see their goals as challenges and manage to keep their motivations elevated (Snyder, 2002). High-hope individuals may pursue even easy goals in a fashion that makes them unique and challenging (Snyder & Fromkin, 1980). On the other hand, low-hope individuals tend to have fewer and more avoidance-based goals (Langelle, 1989). Comparatively speaking, their goals often are more vaguely defined, making them harder to achieve. Snyder (2002) theorized that a low-hope person's goals often require either little effort to attain or are so ambitious that they are impossible to achieve. Low-hope individuals also appear to have deficiencies in pathways thinking: They create comparatively few potential pathways to desired goals (Yoshinobu, 1989), and are hypothesized to stick to the first pathway that comes to mind (Snyder, 2002). Deficiencies in creating pathways present problems if goal blockages are encountered. Whereas high-hopers tend to view obstacles as challenges, low-hopers may be discouraged by them (Irving, Snyder, Crowson, 1998), leading them to invest less energy in the goal pursuit or, perhaps, to relinquish the pursuit altogether (Snyder, 1999).

High- as compared to low-hope people use more effective thinking and behavior throughout goal pursuit sequences (Anderson, 1988). Most high-hopers have many strategies, such as positive self-talk and a preference for positive self-referential input, to boost their agency thinking. In contrast, low-hopers have comparatively little faith in their goal pursuits (Anderson, 1988) and tend to focus on negative input and earlier failures, resulting in depleted confidence and motivation (Snyder, LaPointe, Crowson Jr., & Early, 1998).

Hope and Coping

Important relationships can be viewed as goals in themselves. Additionally, a large number of our goals are associated with significant relationships in our life (Snyder, 2000b). When a child receives a diagnosis of autism, this often means that many of the goals the parent had for the relationship will be lost or impossible to reach. Snyder (2002) views such incidents as barriers or obstacles to goal pursuit.

Encountering barriers to goal pursuits produces negative emotions and lowered agency in people of all hope levels (Rakke, 1997). High-hope people are believed to be more adept at creating alternative pathways, however, and they should therefore experience less long-term stress from the barrier. Because people who are high in hope tend to view stressors as challenges, they are believed to regain agency more quickly after hitting an obstacle. People who are low in hope will, on the other hand, be discouraged and might lose agency for an extended period of time (Snyder, 1996).

In the case of a loss situation such as that encountered when a child has autism, new pathways are not always possible. The goal of having a normal child who will reach usual milestones such as learning to talk, graduating from college or getting married is no longer possible. Snyder (1998) believed that losses should and will be mourned no matter what a person's hope level is. Receiving a diagnosis of autism is theorized to cause a shutdown of hopeful thinking. High hope people, however, are likely to rebound faster than their low-hope counterparts from the negative mood created by such loss. Snyder (1996) claimed that people who are high in hope have an easier time disengaging from impossible-to-reach goals than those who are low in hope. Because people with high hope have more goals in more domains than

people who are low in hope, they will be better able to turn their focus to alternative goals (Snyder et al., 1998).

Desperately clinging to an impossible goal is a negative goal pursuit strategy that entails avoidance of reality. Snyder (2002) suggests that while high-hope people might have a somewhat overly positive view of the world and their goal pursuits, this is a positive strategy that helps keep motivation up. High-hope people should be able to see when there is no possibility of reaching a goal, and then focus on more positive coping strategies. Theoretically, low-hope people have a tendency to cling to impossible goals, and to be less able to cope with stressors in a positive fashion.

People who are high in hope are also better at finding meaning in a loss situation (Affleck & Tennen, 1996; Tennen & Affleck, 1999). While having a child with autism can add many stressors, high-hope people should be better able to find positive aspects even in this situation. One way of doing this might be to notice what positive aspects the child brings to the family and their lives and to find consolation and encouragement in small improvements. This has been found to be an effective coping mechanism for parents of children with intellectual disabilities (Grant & Whittell, 2000). People who are low in hope focus more on the negative aspects of situations, which, in turn, negatively affects their coping (Michael, 2000). In a study of people with fibromyalgia (Affleck & Tennen, 1996) it was found that those who were high in hope coped better than those who were low in hope because they were better able to notice positive aspects of their situation.

The way high-hope people deal with loss and stressors is similar to the coping strategy of reframing. People who are high in hope usually have a number of goals and are able to embrace a substitute goal if one goal is no longer available (Anderson, 1988). By reappraising the

situation they are able to find new goals and new meaning. Snyder (2000) believed this reframing is positive because it keeps them actively working toward goals which, in turn, leads to positive emotions. To illustrate, in a study of hope in women with breast cancer (Stanton et al., 2000), high hope was associated with more positive coping and greater well-being.

The ability of high-hope people to focus on the positive aspects of life has been hypothesized to be a factor behind the relationship between hope and mental well-being (Snyder, 2002). Several studies have found a negative correlation between levels of hope and depression (Snyder et al., 1991). Studies have also found that high hope people report fewer mental health issues on the Minnesota Multiphasic Personality Inventory (MMPI) (Cramer & Dyrkacz, 1998; Irving et al., 1990). Additionally, high-hope people report more positive affect and less negative affect on the Positive and Negative Affect Scale (PANAS) than their low-hope counterparts (Snyder et al., 1991). These results show that hope is positively associated with mental health and might be expected to show a similar relationship among people dealing with the stressors of having a child with autism.

Hope also has been found to help people cope with pain. In a study where participants were subjected to the cold pressor task (Snyder et al., 2005), a painful but harmless task where they have to keep their hand in ice-cold water, high-hopers were able to keep their hands in the water twice as long as the low-hopers. The people who were high in hope reported that they focused on thoughts of successful goal pursuit rather than thoughts about the pain they were experiencing. Snyder (1998) believed a similar process is seen when high-hope people deal with pain in general. Snyder opined that they are able to find meaning by placing their pain in a larger life context and by using positive strategies to cope. This ability to find meaning in hardship

could also be expected to help parents cope with the pain and stress they are experiencing by having a child with autism.

Hope has also been found to be associated with many of the positive coping strategies mentioned previously. High hope has been associated with better social adjustment, more social support and stronger attachment bonds (Kwon, 2002; Shorey, Snyder, Yang, & Lewin, 2003). As social support has been found to improve coping in parents of children with autism, it is expected that high-hopers should fare better than low-hopers because they will have a larger and stronger network to turn to for support.

Sense of coherence is another factor that has been linked to positive coping and hope. High hope is similar to SOC in several ways. SOC is linked to expectations about having the resources and the motivation to deal with the challenges from the environment (Mak et al., 2007). This appears similar to high-hope people believing in their ability to create pathways toward goals and also having the agency to follow these pathways (Snyder et al., 1991). People who are high in hope will, similarly to those who are high in SOC, view stressors as challenges and use problem solving rather than emotion regulation as a coping mechanism (Olsson & Hwang, 2002). In a study of 139 college students, a .70 correlation was found between hope and SOC, showing that, as hope increases, SOC also increases (Feldman & Snyder, 2005).

Hope has been linked to self efficacy with people high in hope having greater self-efficacy than those who are low in hope (Magaletta & Oliver, 1999). Several aspects of self-efficacy theory are similar to hope theory. Outcome expectancy, or analyzing the contingencies in goal attainment situations, is similar to pathways thinking in hope theory. Efficacy expectancy, or evaluation of ability to reach the wanted outcome, is similar to agency (Snyder, 2002). Both hope and self efficacy involve beliefs about one's ability to reach goals and, because

self efficacy has been linked to positive coping in parents of children with autism, hope might be expected to have a similar effect.

Hope has many similarities with hardiness. People who are high in hope are believed to be focused in their goal pursuit, similar to commitment in hardiness. High-hope people believe they have the resources and skills to reach their goals, similar to control in hardiness. High-hopers also view stressors as natural and challenges to be overcome, similar to challenge in the hardiness theory (Snyder, 1994). Green, Grant, and Rynsaardt (2007) found a positive correlation between level of hope and hardiness. This again strengthens the possibility of a connection between hope and healthy coping in parents of children with autism.

A study by Shogren, Lopez, Wehmeyer, Little, and Pressgrove (2006) found that high hope was associated with internal locus of control while low hope was associated with external locus of control. People who are high in hope believe they are able to influence their environment, while those who are low in hope believe the power lies outside of their control. This makes sense from a goal pursuit standpoint, where a belief in one's ability to affect different situations would be required to have an expectation of reaching goals (Snyder, 2002). As an internal locus of control has been found to be positive for coping in parents of children with autism, high-hope people should show better coping as compared to low-hope people.

Optimism is another personality factor that has been shown to have a strong connection with hope (Snyder, 2002). Similarly to optimists, people who are high in hope would be expected to have a positive outlook on goal pursuits and also on life in general. Similar to what is found in pessimists, low hope people tend to have negative expectations toward goal pursuits and life. Several studies have found a .50 correlation between hope scores and LOT scores, showing that, with increasing hope, the likelihood of being considered an optimist also increases.

Hope has many aspects that would be strengths when coping with the stressors of having a child with autism. Additionally, many factors that have been shown to help coping in this group have also been linked to hope. Hope theory seems to fit well with Copley and Bodensteiner's (1987) two-phase theory of chronic sorrow and other studies of chronic sorrow in parents of children with autism (e.g. Roos, 2002). While most parents are expected to experience chronic sorrow, it has been found that those who are able to find substitute goals, such as advocating for their child or all people with autism, report lower levels of chronic sorrow. This is viewed as the second and milder phase of Copley and Bodensteiner's model. As discussed above, high-hope people have many goals and are better able than their low-hope counterparts to find new goals to focus on when one goal is blocked. People who are high in hope should therefore be more likely to reach the milder second phase of chronic sorrow than those who are low in hope.

Design and Methods

The current study was designed to look at the relationship between level of hope and coping in parents of children with autism. As described above, hope has many characteristics that should make it an important factor in coping, but it would also be expected that having a child with autism can reduce a parent's level of hope. Based on these assumptions it was expected that people who are higher in hope would have lower ratings of chronic sorrow and mental health issues, and that increased severity of autism would be related to decreased levels of hope. The study also investigated how hope influences the relationship between the child's severity of autism and reported mental health and chronic sorrow in the parent. It was expected that hope would work as a moderator variable in the relationship between severity of autism symptoms and reported mental health problems. High-hope people were expected to be less affected by

increased autism severity as measured by the Autism Treatment Evaluation Checklist than low-hope people. Hope was expected to have the same effect on the relationship between autism severity and chronic sorrow.

The study also looked specifically at the hope parents have for their child. It is likely that this will be greatly affected by receiving a diagnosis of autism, but it was expected that people who are high in trait hope would have higher hope for their child and, in turn, lower ratings of mental health issues and chronic sorrow. Again, parents' hope for their child was expected to moderate the relationship between autism symptom severity, reported mental health problems and chronic sorrow, with high-hope parents being less affected by symptom severity than those who are low in hope. The effect of parents' hope for their child was expected to be especially strong on the relationship between autism severity and chronic sorrow because the ability to formulate new goals for their child should be essential for positive coping.

It was hypothesized that both hope and parent's hope for their child would moderate the effect of symptom severity on mental health and sorrow. Hope is defined by Snyder (2002) as a trait variable, and was therefore expected to work as a moderator rather than a mediator variable. However, as mentioned above, Snyder theorizes that all people, regardless of hope level, experience a depletion of hope as a result of loss. Hope may work as a partially mediating variable during the time period immediately after diagnosis, with the loss leading to lower hope which, in turn, can have an effect on mental health and chronic sorrow. People high in trait hope would be expected to return to normal levels of hope within a short period of time, while people who are low in hope should remain at a lower level of hope or need a more extended period of time to return to their previous hope level. Data for the length of time since the diagnosis were

therefore collected as this could have a potential influence on hope and also the effect of hope on the relationship between symptom severity and mental health.

Parents' satisfaction with the social and formal support they receive was also measured because both hope and coping in parents of children with autism have been linked to this factor. It was expected that that there would be a positive relationship between hope and satisfaction with support, as well as a positive relationship between parents' hope for their child and satisfaction with support. Additionally, it was expected that there would be a negative relationship between satisfaction with support and mental health problems, and a negative relationship between satisfaction with support and levels of chronic sorrow. Satisfaction with support was used as a control variable in several of the analyzed models.

Structural equation modeling (SEM) techniques were used to analyze the data, as these provide more powerful ways to detect significant relationships between the different variables and also to find a model that gives a good representation of the data. SEM techniques allow for correction of measurement errors, in turn providing greater power to find significant relationships between the variables. SEM was also preferable as confirmatory factor analysis provided validity and reliability information for the newly formulated parents' hope for their child instrument.

To summarize, the stated hypotheses for the proposed study were as follows: 1.) All hypothesized main effects are provided in Table 1. 2.) Trait hope, as measured by the HS-R2, would have a moderating effect on the relationship between autism symptom severity, as measured by the ATEC, and mental health, as measured by the MHI. 2.) Trait hope, as measured by the HS-R2, would have a moderating effect on the relationship between autism symptom severity, as measured by the ATEC, and severity of chronic sorrow, as measured by the KCSI.

3.) Parents' hope for their child would have a moderating effect on the relationship between autism symptom severity, as measured by the ATEC, and mental health, as measured by the MHI. 4.) Parents' hope for their child would have a moderating effect on the relationship between autism symptom severity, as measured by the ATEC, and level of chronic sorrow, as measured by the KCSI.

Table 1.

Correlation Matrix with Expected Direction of Correlations						
	ATEC	Hope	Parents' hope for their child	MHI	Chronic Sorrow	Satisfaction with Support
ATEC	1.00					
Hope	-	1.00				
Parents' hope for their child	--	++	1.00			
MHI	+	-	-	1.00		
Chronic Sorrow	++	-	--	++	1.00	
Satisfaction with Support	-	+	+	-	-	1.00

Participants

Four hundred and two parents (Mean age=42.41) of children with an Autism Spectrum Disorder participated in the study. The sample consisted of 302 mothers and 100 fathers. Only parents of children with Autistic Disorder, Asperger's Disorder, and PDD-NOS were sampled. Parents of children diagnosed with Rett Disorder or Childhood Disintegrative Disorder were not included in the sample as these diagnoses are rare and include additional severe symptoms not

seen in the other Autism Spectrum Disorders. No limits were placed on the sample related to the age of the child or length of time since diagnosis, but data were collected to see if these factors affected the results.

Procedure

E-mails including a request for individuals to participate in the study, information about the study, and a link to the questionnaire were sent to members of local chapters of the Autism Society of America (ASA). ASA is the largest support organization for families with a member with autism, with 200 local chapters and almost 120,000 members spread throughout the USA (ASA, 2008). ASA does not have any available data on the demographics of their members. However, with the size of their membership base it was expected that their members would be representative of families of children with autism and that the sample would include families with children with a wide range of autism severity.

The questionnaire was located on the webpage SurveyMonkey.com. Numerous studies have found that data collected from participants through the internet yield comparable results to those found when collecting data using paper and pencil in a lab (e.g. Cronk & West, 2002; Fouladi, McCarthy, & Moller, 2002; Hewson & Charlton, 2005; Meyerson & Tryon, 2003; Salgado & Moscoso, 2003). A few researchers have proposed that data collected via the internet might be preferable when studying sensitive topics, as studies have found that people show less social desirability and more self disclosure when completing online surveys as compared to paper and pencil in a lab or through mail (Davis, 1999; Joinson, 1999). One potential limitation of collecting data through the internet is that some studies have found a somewhat lower response rate for this method as compared to other data collection methods (Cronk & West, 2002; Mehta & Sivadas, 1995). It was not possible to obtain an accurate estimate of the response

rate in the current study as the e-mails initially were sent to ASA chapter representatives who then distributed them to their members. When accessing SurveyMonkey, participants first reached a page with an informed consent form explaining that the study involved no potential harm, and that the study might be beneficial in clarifying important coping factors for parents of children with autism (see appendix A). Participants were informed that they provided their consent to participate in the study by continuing to the questionnaire.

The participants were asked to fill out a questionnaire consisting of a demographics form, the Autism Treatment Evaluation Checklist, the Snyder Hope Scale, Parents' Hope for their Child Scale, the Mental Health Inventory, the Kendall Chronic Sorrow Instrument, and the Family Quality of Life survey (see appendices B-H). The questionnaires were put in six different orders based on a Latin square design to reduce possible order effects. Each version of the survey had a specific link on SurveyMonkey, and each link was provided to an identical number of different local chapter representatives based on a random division of all of the local ASA chapters. The survey took between 20 and 30 minutes to complete. When participants completed the questionnaire they accessed a short debriefing statement informing them that the study was intended to examine how level of hope affects the relationship between autism symptoms and reported mental health.

Measures

Autism Treatment Evaluation Checklist (ATEC)

The Autism Treatment Evaluation Checklist (ATEC; Rimland, 2000; see Appendix C) was used to measure the severity of autism symptoms. The scale has 77 items measuring functioning in four areas; 1) Speech/Language/Communication -- 14 items; 2) Sociability -- 20 items; 3) Sensory/Cognitive Awareness -- 18 items, and 4) Health/Physical/Behavior -- 25 items.

The items are scored on a four-point scale for the Health/Physical/Behavior subscale with "Not a Problem" (0), "Minor Problem" (1), Moderate Problem (2), and Serious Problem (3) as answer options, and a three-point scale for the other subscales with "Not Descriptive" (0),"Somewhat Descriptive" (1), and "Very Descriptive" (2) as answer options. The scale gives a rating of severity in each of the four separate areas and also an overall symptom severity level. The overall score can range from 0 to 179, and the ceilings for the subscales are 28 for Speech/Language/Communication, 40 for Sociability, 35 for Sensory/Cognitive Awareness, and 75 for Health/Physical/Behavior, with higher scores indicating greater impairment.

Although the scale was originally created to measure progress in children with autism as a result of treatment, the scale has also been found to work well as a measure of symptom severity and developmental level (Charman, Howlin, Berry, & Prince, 2004; Cohen & Padolsky, 2007). Scores on the ATEC have been found to be highly correlated with scores on other often-used measurements of Autism Spectrum Disorder diagnosis and severity, including the Social Communication Questionnaire, the Vineland Adaptive Behavior Scales (Charman et al., 2004), the Gilliam Asperger's Disorder Scale, and the Gilliam Autism Rating Scale (Cohen & Padolsky, 2007). A baseline study of 1358 ratings provided evidence for high internal consistency for the scale, with split-half coefficient of .942 for the overall scale and coefficients ranging from .815 to .920 for the subscales (Rimland, 2000). Scores on the different ATEC subscales have been found to be highly correlated and the overall scale has demonstrated good internal consistency (Rimland, 2000).

The Snyder Hope Scale.

The Snyder Hope Scale (HS-R2; Shorey et al., in press; See Appendix D), is a revised version of the Trait Hope Scale (Snyder, Harris, et al., 1991). It was used to determine the level

of trait hope as this instrument is supposed to measure a stable form of hope. This scale consists of 18 items: 6 Pathways items, 6 Agency items, and 6 Goal items. The items are rated on an 8-point Likert scale ranging from Definitely False to Definitely True. Half of the items are reverse-scored. The Snyder Hope scale has been found to be a reliable and valid measure of the trait hope construct (Shorey et al., in press). Cronbach's alphas for internal consistency reliability ranged from .86 to .88. for the overall scale and from .64 to .81 for the subscales. Test-retest reliabilities over a ten-week period ranged from .47 to .68 for the subscales and .62 for the total scale. Confirmatory factor analysis demonstrated excellent fit for the overall hope model (χ^2 154.83, df = 72, $p < .01$, RMSEA = .059 (90% CI = .045; .072), NNFI = .98, CFI = .99). In addition, generalizability of the model was established with multi-group factor analysis. Across three samples, the Snyder Hope Scale evidenced strong metric invariance, and equality of variances, covariances, and latent means. The hope scale was created to be used within an SEM framework, and studies have found that overall hope functions well as a latent variable (Shorey et al., in press).

Parents' Hope for Their Child Scale (PHC)

A scale measuring parents' hope for their child was generated for the current study (see Appendix E). The scale was created by changing the language of the Snyder Hope Scale to specifically inquire about goals, pathways, and agency related to the child. Answer choices and number of items are identical to those of the Snyder Hope Scale. Reliability and validity indices for the Parents' Hope for Their Child Scale were collected in the current study and will be presented later in this document.

Mental Health Inventory (MHI)

The Mental Health Inventory (MHI; Davies et al., 1988; see Appendix F) was used to assess mental health status. The three subscales Anxiety, Depression, and General Positive Affect were used in the current study. The three subscales together consist of 23 items, 22 scored on a six-choice response scale and one on a five-choice response scale. The MHI was designed for use in nonclinical samples. It has been found to have good internal consistency with Cronbach's alphas for the scales ranging from .92 to .96. Test-retest reliabilities over a one-year period ranged from .54 to .64 (Veit & Ware, 1983).

Kendall Chronic Sorrow Instrument (KCSI)

The Kendall Chronic Sorrow Instrument (KCSI; Kendall, 2005; see Appendix G) was used to measure level of chronic sorrow. The instrument consists of 18 items rated on a 6-point Likert-scale ranging from Almost Always to Almost Never. Higher scores indicate increased possibility of chronic sorrow. Based on a conceptual definition of chronic sorrow, the author suggests that scores between 39 and 82 entail "likely chronic sorrow present" and scores of 83 and over entail "chronic sorrow present". The instrument has so far only been tested as part of a dissertation study that included 145 participants who had experienced different types of losses that would be expected to result in chronic sorrow (Kendall, 2005). This study found that the instrument had good internal consistency, with a Cronbach's alpha of .91. Convergent validity was evidenced by a .68 correlation between the KSCI and the Center for Epidemiologic Studies – Depression Scale (CES-D), an instrument measuring depression, a concept related to chronic sorrow. The KCSI was also found to have a -.71 correlation with the General Well Being Scale (GWBS), a scale measuring well-being, a concept that should be contrary to chronic sorrow.

Family Quality of Life (FQOL)

Items from the Family Quality of Life questionnaire (FQOL; Hoffman, Marquis, Poston, Summers, & Turnbull, 2006) were used to measure the social support the parents are receiving and how satisfied they are with this support. This is a self-report questionnaire consisting of 25 items. The items are rated on a five-point Likert scale ranging from Very Dissatisfied to Very Satisfied. The instrument measures satisfaction with support in five domains: Family Interaction, Parenting, Emotional Well-being, Physical/Material Well-being, and Disability-Related support. The scale has evidenced good internal consistency with a Cronbach's alpha of .88. The scale also has shown good test-retest reliability, with correlations between time points ranging from .60 to .77 for the different domains. Confirmatory factor analysis demonstrated that the item-level overall FQOL model had acceptable fit ($\chi^2$617.28, df = 270, $p < .001$, RMSEA = .07, CFI = .87) and that the subscale-level FQOL model had excellent fit ($\chi^2$3.41, df = 5, p=.63, RMSEA = .00, CFI = 1.00). Convergent validity was evidenced by significant correlations between the FQOL Family Interaction subscale and the Family APGAR, a measure of family functioning, and between the FQOL Physical/Material Well-Being subscale and the Family Resource Scale, a measure of family resources. The FQOL was created to work in SEM models, and studies have found that the overall FQOL construct works well as a latent variable (Hoffman et al., 2006). For the current study, eleven items were chosen to provide a control variable for satisfaction with support (see appendix H). Three items from the Disability-Related support subscale and two items each from the other four FQOL domains were selected based on their loading on the overall FQOL and also based on face validity.

Results

The overall sample of questionnaires contained 7.2% missing data. The missing data were evenly distributed among the study questionnaires. In every case of missing data, data were missing on a questionnaire level rather than an item level; if the participant missed one item on a particular questionnaire they would also be missing all other items on this questionnaire. This was most likely an effect of the data being gathered online and participants selecting to discontinue or possibly losing internet connection before moving to the next section of the survey. Missingness was most likely dependent on amount of time needed to complete the survey rather than the variable itself or the values of other variables in study, and the data can therefore be assumed to be missing at random. Since six different versions of the survey with six different orders of the questionnaires were used, the amount of missing data was comparable across questionnaires and the possibility of order effects was reduced. Missing data were addressed by using the full information maximum likelihood (FIML) estimator in M*plus* 5.21. This method utilizes all available information to provide estimates of the model parameters and standard errors. Enders (2006) found that this missing data estimation method provides comparable or superior results to other methods such as pairwise deletion and multiple imputation. Additionally, FIML should provide unbiased and efficient results with data missing completely at random or missing at random at the level of missingness seen in the current study (Enders & Bandalos, 2001; Schafer & Graham, 2002).

Descriptive Statistics

The final sample included 302 females and 100 males. The mean age for the parents in the sample was 42.41 (range = 25 to 87). The ethnic breakdown of the sample was as follows: White 360 (89.6%), African American 12 (3%), Hispanic 11 (2.7%), Asian 11 (2.7%), other

(mostly biracial) 5 (1.3%), American Indian 2 (0.5%), and Middle Eastern 1 (0.2%). Of the parents in the sample, 325 were married (80.8%), 42 were divorced (10.4%), 8 were separated (2%), 21 were single (5.2%), and 6 were living with a domestic partner (1.5%).

The mean number of children per family in the sample was 2.17 (range = 1 to 8). Three-hundred and fifty-seven of the respondents had one child with autism, while 41 had two children with autism, and 3 of the participants had 3 children with autism. If the respondents had more than one child with autism, they were asked to focus on one of them when answering the specific questions. The mean age of the child with autism was 10.96 (range = 2 to 49), and the mean age at diagnosis was 4.54 (range = 1 to 24). Autistic disorder was the most common primary diagnosis covering 244 of the children in the sample, 105 had Asperger's Disorder as primary diagnosis, and 97 were diagnosed with PDD-NOS. Many of the children were listed as having more than one Pervasive Developmental Disorder diagnosis, even though these disorders should be mutually exclusive. Furthermore, 182 of the children in the sample were reported to have an additional diagnosis such as Attention-Deficit Hyperactivity Disorder, Tourette's Syndrome and Seizure Disorder. Due to the uncertainty of the reported diagnosis and possible additional diagnoses, it was decided to only use the scores from the ATEC as a basis for autism severity in the analysis.

All of the scales and subscales of the different measures evidenced adequate internal consistency with Cronbach's alphas between .937 and .718. The alphas for the Snyder Hope Scale were: Full Scale=.919, Goals subscale=.809, Pathways subscale=.810, and Agency subscale=.799. The alphas for the Parents' Hope for Their Child Scale were: Full Scale=.891, Goals subscale=.738, Pathways subscale=.798, and Agency subscale=.718. Although the Parents' Hope for Their Child Scale had slightly lower alphas than the Snyder Hope Scale, all of

the alphas were within acceptable limits. The Parents' Hope for Their Child Scale has acceptable internal reliability and appears to measure a single unidimensional latent construct.

The means and standard deviations for the different full scales and subscales are given by total sample and by gender in Table 2. The mean for the KCSI was 53.89, and the range was 19 to 105. Two-hundred and seventy-six of the participants scored in the range on KCSI where chronic sorrow is likely present, 20 scored in the range where chronic sorrow is present, and 67 participants had a score indicating that chronic sorrow is not present. The mean for the full ATEC and all of the subscales were in the mild to moderate range, and the full ATEC and all of the subscales had a wide range of scores. A nested model chi square difference test was performed to test if the full scale and subscale means of the HS-R2 were significantly different from the PHC full scale and subscale means. The mean for the full HS-R2 (M=6.22) in the sample was significantly higher than the mean for the full PHC (M=6.04, $\Delta\chi^2(1) = 3.9$, $p < .05$). The mean for the Goals subscale of the HS-R2 (M=6.01) in the sample was significantly lower than the mean for the Goals subscale of the PHC (M=6.13, $\Delta\chi^2(1) = 3.9$, $p < .05$). The mean for the Pathways subscale of the HS-R2 (M=6.22) in the sample was significantly higher than the mean for the Pathways subscale of the PHC (M=5.57, $\Delta\chi^2(1) = 96.97$, $p < .001$). The mean for the Agency subscale of the HS-R2 (M=6.43), although slightly lower, was not significantly different from the mean of the Agency subscale of the PHC (M=6.44, $\Delta\chi^2(1) = .074$, $p > .05$).

The means for the full HS-R2, all of the HS-R2 subscales, and the three MHI subscales were compared to means from a sample of college students by conducting an independent samples *t*-test in SPSS Statistics 17.0. Data for the college sample were originally collected for a different study (Monsson, 2007). The means, the differences between the means, the *t* values for these differences, and the *p* values are presented in Table 3. There were no significant

Table 2.

Full Scale and Subscale Means for all Measures by Total Sample and Gender									
	Total Sample			Females			Males		
	N	*M*	*SD*	*N*	*M*	*SD*	*N*	*M*	*SD*
HS-R2 Goals	365	6.01	1.18	275	6.01	1.20	90	6.02	1.11
HS-R2 Pathways	365	6.22	1.12	275	6.21	1.10	90	6.26	1.19
HS-R2 Agency	365	6.42	1.15	275	6.42	1.13	90	6.41	1.19
HS-R2 Full Scale	365	6.22	1.05	275	6.22	1.04	90	6.23	1.06
PHC Goals	363	6.13	1.13	272	6.11	1.11	91	6.16	1.20
PHC Pathways	363	5.57	1.24	272	5.56	1.21	91	5.60	1.34
PHC Agency	363	6.42	1.03	272	6.41	1.01	91	6.43	1.09
PHC Full Scale	363	6.04	1.00	272	6.03	.97	91	6.06	1.11
KCSI	363	53.93	16.73	271	53.94	16.44	92	53.89	17.64
FQOL Family Interaction	358	3.96	.90	268	4.01	.89	90	3.80	.91
FQOL Parenting	358	3.83	.87	268	3.84	.85	90	3.81	.94
FQOL Emotional Well-being	358	3.08	1.14	268	3.10	1.13	90	3.03	.1.16
FQOL Physical/Material Well-being	358	3.91	.94	268	3.91	.94	90	3.91	.95
FQOL Disability Related Support	358	3.83	.88	268	3.84	.89	90	3.78	.85
FQOL Full Scale	358	3.73	.71	268	3.75	.70	90	3.67	.75
MHI Anxiety	351	2.72	.91	262	2.73	.89	89	2.68	.97
MHI Depression	351	2.63	.94	262	2.62	.92	89	2.65	.98
MHI General Positive Affect	351	3.76	1.01	262	3.77	.98	89	3.73	1.11
ATEC Speech/ Language/ Communication	352	7.28	7.10	263	7.57	7.16	89	6.44	6.91
ATEC Sociability	352	12.37	7.43	263	12.63	7.34	89	11.60	7.70
ATEC Sensory/Cognitive Awareness	352	12.16	7.71	263	12.67	7.66	89	10.64	7.69
ATEC Health/Physical/ Behavior	352	21.01	11.59	263	21.65	11.83	89	19.12	10.70
ATEC Full Scale	352	52.83	27.50	263	54.53	27.87	89	47.80	25.86

Table 3.

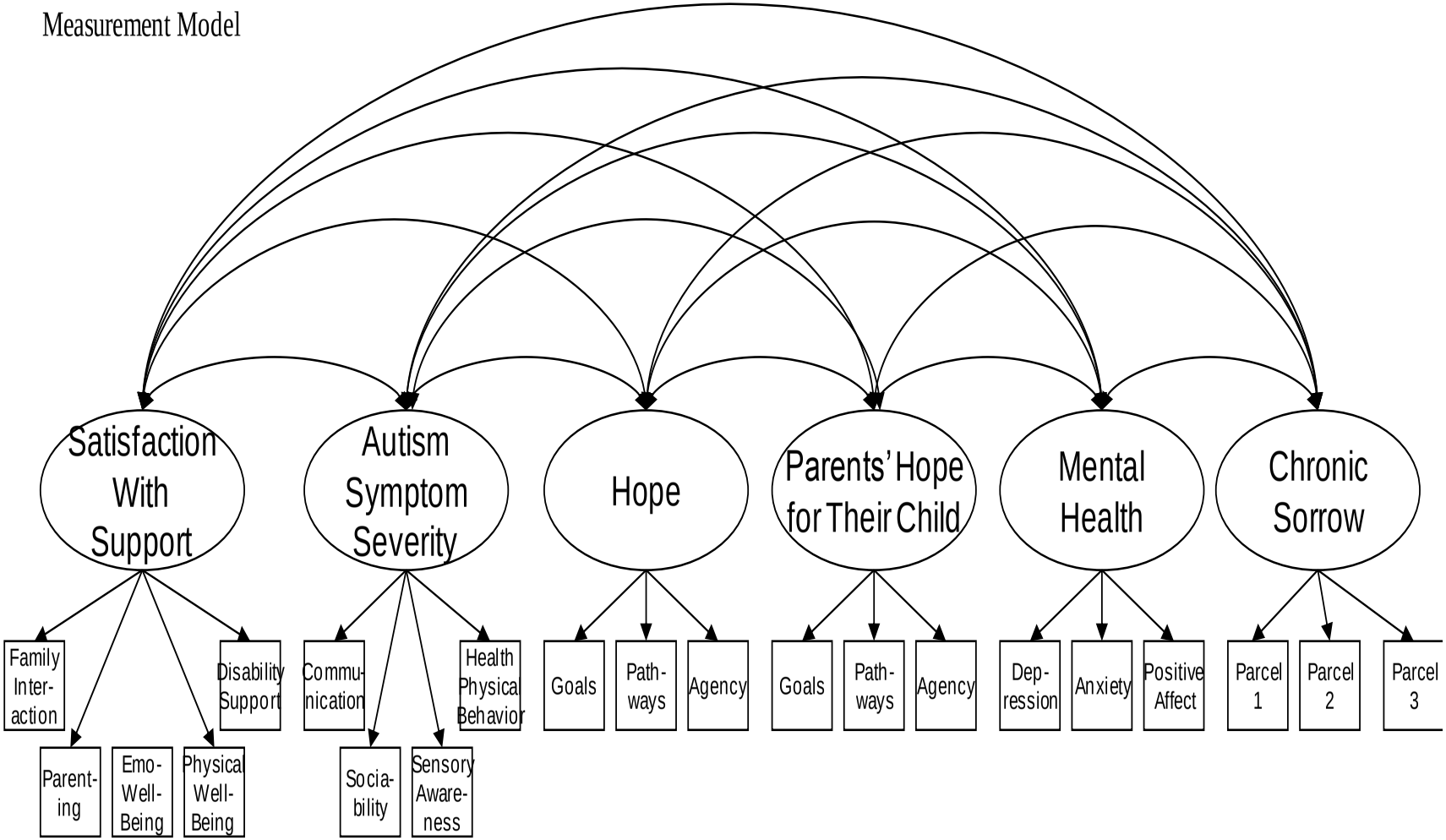
Hope and Mental Health in Parents of Children with Autism Compared with College Students					
	Mean Parent Sample	Mean College Sample	Mean Difference	*t* value	*p*
HS-R2 Full Scale	6.22	6.17	.052	.580	ns
HS-R2 Goals	6.01	6.05	.040	-.374	ns
HS-R2 Pathways	6.22	6.16	.067	.724	ns
HS-R2 Agency	6.42	6.29	.129	1.218	ns
MHI Depression	2.63	2.28	.345	4.196	<.001
MHI Anxiety	2.72	2.55	.171	2.070	<.05
MHI Positive Affect	3.76	3.83	-.071	-.826	ns

differences between overall hope, the hope subscales, and positive affect between the two samples. The means for the Anxiety subscale and the Depression subscale were found to be significantly higher in parents of children with autism than in college students.

Measurement Model

In order to test how the different latent variables worked together in a model and to find the correlation between the variables, a measurement model with all of the variables was created. The measurement model was first run as proposed in Figure 1. Autism symptom severity, hope, parents' hope for their child, chronic sorrow, satisfaction with support, and mental health were entered as latent variables. For hope and parents' hope for their child, the goals, pathways, and agency subscales were used as indicators. Because the Kendall Chronic Sorrow Instrument does not have established subscales, three random parcels were created to provide multiple indicators

Figure 1. Proposed Measurement Model



for the latent variable of chronic sorrow. For the satisfaction with support variable the Family Interaction, Parenting, Emotional Well-Being, Physical/Material Well-Being, and Disability Related Support subscales of the FQOL were used as indicators. For the mental health variable the Depression, Anxiety, and General Positive Affect scales of the MHI were used as indicators. For autism severity the Speech/Language/Communication, Sociability, Sensory/Cognitive Awareness, and Health/Physical/Behavior subscales of the ATEC were used as indicators.

The initial measurement model did not reach acceptable model fit. The poor model fit was largely due to the ATEC subscales together not representing a unidimensional construct. Especially the Health/Physical/Behavior subscale had rather low correlations with the other subscales (.37, .55, .55). This scale identifies a range of different physical and behavioral issues that are common in children with autism; however, these problems do not necessarily appear together, and in some of the cases they might even be contrary issues (for example lethargy and hyperactivity). Additionally, as described previously, while the different health problems and problem behaviors are often present in children with autism they do not automatically go together with other symptoms seen in autism. The difficulties with the ATEC scale as a unidimensional construct might represent a general complexity with autism as a diagnosis. Autism Spectrum Disorders are as the name implies disorders on a spectrum, with many different mixtures of symptoms and severities of symptoms all qualifying for a diagnosis. Studies have found that there might be several different subtypes of Autism Spectrum Disorders in addition to those defined in the DSM-IV (Beglinger & Smith, 2001; Wing, 2005). In the current study it was decided to include each of the different ATEC subscales as a latent variable in the measurement model. Three random parcels were generated from each subscale to provide indicators for the latent variables.

It was also decided to use the Depression, Anxiety and Positive Affect subscales of the MHI as latent variables rather than indicators of an encompassing mental health construct. Three random parcels were generated as indicators for the anxiety and the positive affect variables. For the depression variable each of the four items of the subscale was used as an indicator. This improved overall model fit of the measurement model, but more importantly, it provided more specific information about the effect of hope and severity of autism symptoms on different aspects of mental health.

The final measurement model is presented in figure 2. The correlations between the latent variables for this model are presented in Table 4. The loadings, residual variances, and squared multiple correlations for each of the indicators are presented in Table 5. This model had acceptable fit on all fit indices (χ^2 (539)=1150.91, p<.0001 , RMSEA=0.054 (90% CI = .050; .059), NNFI=0.946, CFI=0.937). As expected, parents' hope for their child had a significant strong positive correlation with hope. However, the correlation was not so strong that it would indicate that these constructs are identical, providing support for the validity of the PHC scale.

Nested model chi square difference tests were performed to test if the correlations between hope and parents' hope for their child and all other variables were significantly different (see Table 6). Parents' hope for their child had significant negative correlations with chronic sorrow and all autism severity measures, and a significant positive correlation with satisfaction with support. All of these correlations, with the exception of chronic sorrow, were significantly stronger than the same correlation between these variables and hope. Additionally, hope had a significantly stronger negative correlation with anxiety than the same correlation between anxiety and parents' hope for their child. Hope had a stronger negative correlation with depression than the correlation between depression and parents' hope for their child; however,

Figure 2. Actual
Measurement Model

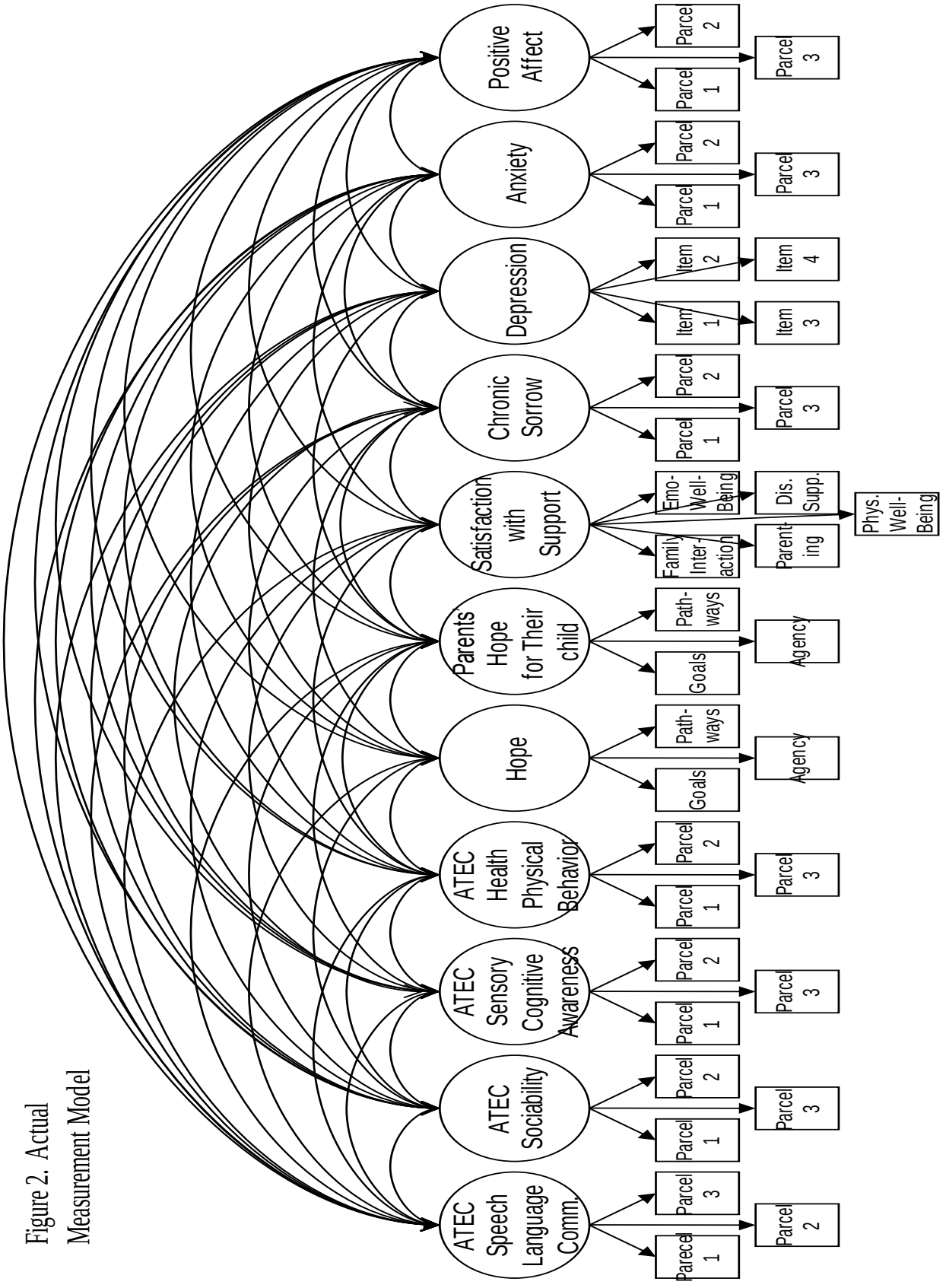


Table 4. Correlations between Latent Constructs for Measurement Model

	ATEC Speech/Language/ Communication	ATEC Sociability	ATEC Sensory/ Cognitive Awareness	ATEC Health/ Physical/ Behavior	Hope	Parents' Hope for Their Child	Satisfaction with Support	Chronic Sorrow	Depression	Anxiety	Positive Affect
ATEC Speech/Language/ Communication	1.00										
ATEC Sociability	0.468** (0.045)	1.00									
ATEC Sensory/ Cognitive Awareness	0.777** (0.024)	0.741** (0.029)	1.00								
ATEC Health/ Physical/Behavior	0.384** (0.050)	0.598** (0.042)	0.599** (0.41)	1.00							
Hope	-0.093 (0.056)	-0.180** (0.057)	-0.192** (0.056)	-0.108 (0.059)	1.00						
Parents' Hope for Their Child	-0.207** (0.056)	-0.396** (0.052)	-0.328** (0.054)	-0.287** (0.057)	0.696** (0.034)	1.00					
Satisfaction with Support	-0.104 (0.059)	-0.247** (0.058)	-0.234** (0.058)	-0.385** (0.055)	0.499** (0.048)	0.615** (0.043)	1.00				
Chronic Sorrow	0.293** (0.051)	0.267** (0.054)	0.348** (0.051)	0.342** (0.053)	-0.379** (0.050)	-0.445** (0.048)	-0.562** (0.044)	1.00			
Depression	0.098 (0.056)	0.060 (0.058)	0.090 (0.057)	0.194** (0.057)	-0.462** (0.047)	-0.305** (0.054)	-0.560** (0.044)	0.607** (0.038)	1.00		
Anxiety	0.113* (0.056)	0.124* (0.057)	0.130* (0.057)	0.332** (0.054)	-0.385** (0.051)	-0.293** (0.055)	-0.486** (0.048)	0.521** (0.044)	0.772** (0.027)	1.00	
Positive Affect	-0.182** (0.054)	-0.191** (0.058)	-0.255** (0.054)	-0.300** (0.054)	0.548** (0.041)	0.484** (0.046)	0.681** (0.035)	-0.645** (0.035)	-0.764** (0.026)	-0.648** (0.035)	1.00

Standard error in parenthesis.
*Significant at $p<.05$
**Significant at $p<.01$

Table 5. Loading and Residuals for Each Indicator for Measurement Model

Indicator	Estimated Loading (SE)	Standardized Loading	Residuals (SE)	R^2
ATEC Speech/Language/Communication:				
Parcel 1	2.38 (0.10)	0.96	0.52 (0.06)	0.92
Parcel 2	2.41 (0.10)	0.97	0.39 (0.06)	0.94
Parcel 3	2.18 (0.10)	0.92	0.89 (0.08)	0.84
ATEC Sociability:				
Parcel 1	2.56 (0.13)	0.87	2.03 (0.22)	0.76
Parcel 2	2.48 (0.12)	0.90	1.48 (0.19)	0.81
Parcel 3	2.02 (0.11)	0.83	1.82 (0.18)	0.69
ATEC Sensory/Cognitive Awareness:				
Parcel 1	2.66 (0.12)	0.90	1.71 (0.18)	0.81
Parcel 2	2.29 (0.11)	0.89	1.45 (0.14)	0.78
Parcel 3	2.46 (0.11)	0.91	1.28 (0.14)	0.83
ATEC Health/Physical/Behavior:				
Parcel 1	3.86 (0.20)	0.87	4.71 (0.61)	0.76
Parcel 2	3.37 (0.19)	0.81	6.14 (0.62)	0.65
Parcel 3	3.60 (0.20)	0.82	6.16 (0.65)	0.68
Snyder Hope Scale (HS-R2):				
Goals	5.82 (0.31)	0.82	16.00 (1.49)	0.68
Pathways	5.71 (0.29)	0.85	13.01 (1.31)	0.72
Agency	6.36 (0.29)	0.92	7.06 (1.15)	0.85

Parents' Hope for Their Child (PHC):				
Goals	4.93 (0.32)	0.73	21.56 (1.85)	0.53
Pathways	6.39 (0.32)	0.86	14.17 (1.65)	0.74
Agency	5.44 (0.27)	0.88	8.35 (1.09)	0.78
Kendall Chronic Sorrow Instrument (KCSI):				
Parcel 1	6.18 (0.26)	0.94	4.88 (0.75)	0.89
Parcel 2	5.12 (0.22)	0.92	4.79 (0.60)	0.85
Parcel 3	4.88 (0.23)	0.88	6.88 (0.65)	0.78
Family Quality of Life:				
Family Interaction	1.15 (0.09)	0.64	1.91 (0.16)	0.41
Parenting	1.44 (0.08)	0.83	0.95 (0.11)	0.69
Emotional Well-Being	1.67 (0.11)	0.73	2.39 (0.22)	0.54
Physical/Material Well-Being	1.05 (0.10)	0.56	2.45 (0.20)	0.31
Disability Related Support	1.83 (0.13)	0.69	3.64 (0.32)	0.48
MHI Depression:				
Item 1	0.71 (0.04)	0.85	0.20 (0.02)	0.71
Item 2	1.01 (0.05)	0.90	0.25 (0.03)	0.80
Item 3	0.88 (0.05)	0.77	0.51 (0.04)	0.60
Item 4	1.00 (0.05)	0.90	0.23 (0.03)	0.81
MHI Anxiety:				
Parcel 1	2.55 (0.12)	0.89	1.80 (0.20)	0.78
Parcel 2	2.55 (0.13)	0.87	2.01 (0.22)	0.76
Parcel 3	2.70 (0.13)	0.90	1.82 (0.22)	0.80

MHI Positive Affect:

Parcel 1	3.82 (0.16)	0.94	1.90 (0.24)	0.89
Parcel 2	3.02 (0.13)	0.92	1.55 (0.17)	0.86
Parcel 3	3.01 (0.13)	0.92	1.68 (0.17)	0.84

Table 6.

Correlation Comparisons Hope and Parents' Hope for Their Child						
	Hope with	Parents' Hope for Their Child with	Original Chi-Square	Equated Chi-Square	Chi-Square Difference	*p*-value
Chronic Sorrow	-0.379	-0.445	1150.911	1152.937	2.026	ns
Satisfaction with Support	0.499	0.615	1150.911	1157.341	6.430	<.05
ATEC Speech/ Language/ Communication	-0.093	-0.207	1150.911	1156.263	5.352	<.05
ATEC Sociability	-0.180	-0.396	1150.911	1170.713	19.802	<.001
ATEC Social/ Cognitive Awareness	-0.192	-0.328	1150.911	1158.624	7.713	<.01
ATEC Health/ Physical/ Behavior	-0.108	-0.287	1150.911	1163.293	12.382	<.001
Depression	-0.426	-0.305	1150.911	1162.076	11.165	.054
Anxiety	-0.385	-0.293	1150.911	1154.610	3.699	<.001
Positive Affect	0.548	0.484	1150.911	1153.110	2.199	ns

this difference was only marginally significant. Hope also had a stronger positive correlation with positive affect than the correlation between positive affect and parents' hope for their child, but this difference did not reach significance. As expected, parents' hope for their child had stronger correlations than hope with variables that are more directly related to the child, while hope had stronger correlations than parents' hope for their child with general mental health variables. These results provide good construct (convergent and discriminant) validity for the new PHC scale.

In order to control for the possibility that the main effects were the results of the influence of satisfaction with support on the different variables, a measurement model was run where support was included as a control variable rather than a latent variable. The partial correlations between the latent variables for this model are presented in Table 7. The loadings, residual variances, and squared multiple correlations for each of the indicators are presented in Table 8. This model had acceptable fit on all fit indices (χ^2 (539)=1150.91, p<.0001 , RMSEA=0.054 (90% CI = .050; .059), NNFI=0.946, CFI=0.937). Partialing out the effect of support had a greater influence on the correlations between parents' hope for their child and the other variables than on the correlations between hope and the other variables. This would be expected as satisfaction with support was found to have a significantly higher correlation with parents' hope for their child than with hope, and also as the amount of family support and specific disability related support would have a greater influence on the goals directly related to the child than on more general goals.

As can be seen from Table 7, partialing out the effects of support reduced the size of the correlation coefficients between .003 and .241 for the relationships between hope and the other variables, and it reduced the size of the correlation coefficients between .024 and .371 for the

Table 7. Correlations between Latent Constructs for Measurement Model Controlled for Effect of Satisfaction with Support

	Satisfaction with Support	ATEC Speech/Language/ Communication	ATEC Sociability	ATEC Sensory/ Cognitive Awareness	ATEC Health/ Physical/ Behavior	Hope	Parents' Hope for Their Child	Chronic Sorrow	Depression	Anxiety	Positive Affect
Satisfaction with Support	1.00										
ATEC Speech/Language/ Communication	--	1.00									
ATEC Sociability	--	0.459** (0.046)	1.00								
ATEC Sensory/ Cognitive Awareness	--	0.778** (0.025)	0.725** (0.031)	1.00							
ATEC Health/Physical/ Behavior	--	0.375** (0.052)	0.563** (0.045)	0.567** (0.044)	1.00						
Hope	--	-0.048 (0.059)	-0.067 (0.061)	-0.089 (0.060)	-0.105 (0.064)	1.00					
Parents' Hope for Their Child	--	-0.183** (0.061)	-0.319** (0.060)	-0.240** (0.061)	-0.069 (0.067)	0.569** (0.048)	1.00				
Chronic Sorrow	--	0.286** (0.055)	0.160** (0.060)	0.269** (0.056)	0.164** (0.062)	-0.138* (0.062)	-0.151* (0.065)	1.00			
Depression	--	0.048 (0.060)	-0.097 (0.062)	-0.051 (0.062)	-0.028 (0.065)	-0.254** (0.060)	0.060 (0.068)	0.427** (0.053)	1.00		
Anxiety	--	0.072 (0.059)	0.005 (0.061)	0.019 (0.061)	0.180** (0.062)	-0.188** (0.061)	0.010 (0.067)	0.342** (0.056)	0.690** (0.037)	1.00	
Positive Affect	--	-0.152* (0.060)	-0.032 (0.064)	-0.135* (0.062)	-0.056 (0.066)	0.327** (0.058)	0.113 (0.068)	-0.433** (0.053)	-0.632** (0.041)	-0.495** (0.050)	1.00

Standard error in parenthesis.
*Significant at $p<.05$
**Significant at $p<.01$

Table 8. Loading and Residuals for Each Indicator for Measurement Model Controlled for Effect of Satisfaction with Support

Indicator	Estimated Loading (SE)	Standardized Loading	Residuals (SE)	R^2
ATEC Speech/Language/Communication:				
Parcel 1	2.37 (0.10)	0.96	0.52 (0.06)	0.92
Parcel 2	2.40 (0.10)	0.97	0.39 (0.06)	0.94
Parcel 3	2.17 (0.10)	0.92	0.89 (0.08)	0.84
ATEC Sociability:				
Parcel 1	2.49 (0.13)	0.87	2.03 (0.22)	0.76
Parcel 2	2.40 (0.12)	0.90	1.48 (0.19)	0.81
Parcel 3	1.96 (0.11)	0.83	1.82 (0.18)	0.69
ATEC Sensory/Cognitive Awareness:				
Parcel 1	2.58 (0.12)	0.90	1.71 (0.18)	0.81
Parcel 2	2.22 (0.11)	0.89	1.45 (0.14)	0.78
Parcel 3	2.40 (0.11)	0.91	1.28 (0.14)	0.83
ATEC Health/Physical/Behavior:				
Parcel 1	3.56 (0.19)	0.87	4.71 (0.61)	0.76
Parcel 2	3.11 (0.18)	0.81	6.14 (0.62)	0.65
Parcel 3	3.33 (0.19)	0.82	6.16 (0.65)	0.68
Snyder Hope Scale (HS-R2):				
Goals	5.04 (0.29)	0.82	16.00 (1.49)	0.68
Pathways	4.95 (0.27)	0.85	13.01 (1.31)	0.72
Agency	5.51 (0.27)	0.92	7.06 (1.15)	0.85

Parents' Hope for Their Child (PHC):				
Goals	3.89 (0.28)	0.73	21.56 (1.85)	0.53
Pathways	5.04 (0.29)	0.86	14.17 (1.65)	0.74
Agency	4.29 (0.25)	0.88	8.35 (1.09)	0.78
Kendall Chronic Sorrow Instrument (KCSI):				
Parcel 1	5.11 (0.25)	0.94	4.88 (0.75)	0.89
Parcel 2	4.24 (0.20)	0.92	4.79 (0.60)	0.85
Parcel 3	4.03 (0.21)	0.88	6.88 (0.65)	0.78
Family Quality of Life:				
Family Interaction	1.15 (0.09)	0.64	1.91 (0.16)	0.41
Parenting	1.44 (0.08)	0.83	0.95 (0.11)	0.69
Emotional Well-Being	1.67 (0.11)	0.73	2.39 (0.22)	0.54
Physical/Material Well-Being	1.05 (0.10)	0.56	2.45 (0.20)	0.31
Disability Related Support	1.83 (0.13)	0.69	3.64 (0.32)	0.48
MHI Depression:				
Item 1	0.58 (0.03)	0.85	0.20 (0.02)	0.71
Item 2	0.83 (0.04)	0.90	0.25 (0.03)	0.80
Item 3	0.72 (0.05)	0.77	0.51 (0.04)	0.60
Item 4	0.83 (0.04)	0.90	0.23 (0.03)	0.81
MHI Anxiety:				
Parcel 1	2.23 (0.12)	0.89	1.80 (0.20)	0.78
Parcel 2	2.23 (0.12)	0.87	2.01 (0.22)	0.76
Parcel 3	2.36 (0.12)	0.90	1.82 (0.22)	0.80

MHI Positive Affect:				
Parcel 1	2.80 (0.14)	0.94	1.90 (0.24)	0.89
Parcel 2	2.21 (0.11)	0.92	1.55 (0.17)	0.86
Parcel 3	2.20 (0.12)	0.92	1.68 (0.17)	0.84

relationships between parents' hope for their child and the other variables. However, most of the previously significant correlations remained highly significant. This shows that the relationships between hope and parents' hope for their child and autism severity, chronic sorrow, and mental health cannot be explained simply by a shared covariance with the satisfaction with the support the family receives. The correlations that were reduced below significance levels were mostly those that were weak prior to partialing out the variance from satisfaction with support.

In order to control for the possibility that the associations between hope and parents' hope for their child and the other latent variables were the results of the effects of gender, income, number of children, number of children with autism, age of the child with autism, and time since diagnosis on the different variables, a measurement model was run where these variables were included as control variables. The beta weights for the effect of the control variables on the latent variables are presented in Table 9. The partial correlations between the latent variables for this model are presented in Table 10. The loadings, residual variances, and squared multiple correlations for each of the indicators are presented in Table 11. This model had acceptable fit on all fit indices (χ^2 (689)=1436.19, p<.0001, RMSEA=0.052 (90% CI = .048; .056), NNFI=0.921, CFI=0.936).

As can be seen from Table 8, gender of the parent did not have a significant effect on any

Table 9. Beta Values for Control Variables on Latent Variables

	ATEC Speech/Language/ Communication	ATEC Sociability	ATEC Sensory/ Cognitive Awareness	ATEC Health/ Physical/ Behavior	Hope	Parents' Hope for Their Child	Satisfaction with Support	Chronic Sorrow	Depression	Anxiety	Positive Affect
Gender	-0.099 (0.126) [0.038]	-0.087 (0.130) [-0.037]	-0.235 (0.129) [-0.097]	-0.191 (132) [-0.081]	-0.031 (0.127) [-0.013]	0.046 (0.129) [0.020]	-0.102 (0.133) [-0.043]	-0.041 (0.124) [-0.018]	0.035 (0.127) [0.015]	-0.052 (0.128) [-0.022]	0.063 (0.125) [0.027]
Income	-0.037** (0.013) [-0.146**]	-0.041** (0.013) [-0.176**]	-0.037** (0.013) [0.304**]	-0.029* (0.014) [-0.125*]	0.018 (0.013) [0.079]	0.008 (0.013) [0.034]	0.020 (0.014) [0.086]	0.016 (0.013) [0.070]	0.003 (0.013) [0.014]	-0.020 (0.013) [-0.088]	-0.008 (0.013) [-0.035]
Number of Children	0.028 (0.055) [0.026]	0.015 (0.057) [0.015]	-0.014 (0.056) [-0.013]	0.033 (0.058) [0.033]	0.017 (0.055) [0.017]	0.062 (0.056) [0.062]	-0.038 (0.057) [-0.038]	-0.117* (0.054) [-0.117*]	0.055 (0.056) [0.055]	0.058 (0.056) [0.058]	-0.025 (0.054) [-0.025]
Number of Children with Autism	-0.100 (0.161) [-0.031]	0.015 (0.057) [0.117*]	0.152 (164) [0.050]	0.122 (0.169) [0.041]	-0.280 (0.161) [-0.095]	-0.338* (0.167) [-0.114*]	-0.283 (0.171) [-0.095]	-0.038 (0.160) [-0.013]	-0.071 (0.163) [-0.024]	0.105 (0.164) [0.058]	-0.014 (0.160) [-0.005]
Time Since Diagnosis	0.100** (0.018) [0.513**]	-0.020 (0.019) [-0.114	0.055** (0.056) [0.304**]	0.017 (0.019) [0.095]	0.025 (0.018) [0.143]	0.054** (0.019) [0.303**]	0.055 (0.018) [0.181]	-0.009 (0.160) [-0.050]	-0.013 (0.018) [-0.074]	0.009 (0.018) [0.050]	0.009 (0.018) [0.049]
Age of Child	-0.132** (0.017) [-0.739**]	0.015 (0.017) [0.091]	-0.060** (0.017) [-0.359**]	-0.030 (0.017) [-0.183]	-0.019 (0.016) [-0.115]	-0.046** (0.017) [-0.282**]	-0.037* (0.017) [-0.228*]	-0.006 (0.016) [-0.038]	-0.007 (0.016) [-0.041]	-0.030 (0.017) [-0.185]	0.011 (0.016) [0.070]

Standard error in parenthesis.
*Significant at $p<.05$
**Significant at $p<.01$
[Completely standardized loading]

Table 10. Correlations between Latent Constructs for Measurement Model Controlled for Gender, Income, Number of Children, Number of Children with Autism, Time since Diagnosis, and Age of Child

	ATEC Speech/Language/ Communication	ATEC Sociability	ATEC Sensory/ Cognitive Awareness	ATEC Health/ Physical/ Behavior	Hope	Parents' Hope for Their Child	Satisfaction with Support	Chronic Sorrow	Depression	Anxiety	Positive Affect
ATEC Speech/Language/ Communication	1.00										
ATEC Sociability	0.527** (0.043)	1.00									
ATEC Sensory/ Cognitive Awareness	0.779** (0.025)	0.762** (0.028)	1.00								
ATEC Health/ Physical/Behavior	0.361** (0.052)	0.595** (0.042)	0.583** (0.42)	1.00							
Hope	-0.120* (0.057)	-0.151** (0.058)	-0.200** (0.056)	-0.099 (0.059)	1.00						
Parents' Hope for Their Child	-0.296** (0.055)	-0.382** (0.053)	-0.366** (0.053)	-0.300** (0.057)	0.690** (0.035)	1.00					
Satisfaction with Support	-0.169** (0.058)	-0.222** (0.059)	-0.263** (0.057)	-0.400** (0.054)	0.487** (0.049)	0.612** (0.043)	1.00				
Chronic Sorrow	0.325** (0.051)	0.301** (0.053)	0.377** (0.050)	0.366** (0.052)	-0.393** (0.050)	-0.459** (0.048)	-0.605** (0.042)	1.00			
Depression	0.096 (0.056)	0.063 (0.058)	0.100 (0.057)	0.197** (0.058)	-0.467** (0.047)	-0.314** (0.054)	-0.575** (0.043)	0.612** (0.038)	1.00		
Anxiety	0.058 (0.057)	0.104 (0.058)	0.101 (0.057)	0.312** (0.055)	-0.384** (0.051)	-0.305** (0.055)	-0.501** (0.048)	0.540** (0.043)	0.777** (0.027)	1.00	
Positive Affect	-0.183** (0.054)	-0.197** (0.056)	-0.266** (0.053)	-0.301** (0.054)	0.556** (0.041)	0.497** (0.046)	0.705** (0.034)	-0.648** (0.035)	-0.762** (0.026)	-0.649** (0.035)	1.00

Standard error in parenthesis.
*Significant at $p<.05$
**Significant at $p<.01$

Table 11. Loading and Residuals for Each Indicator for Measurement Model Controlled for Effect of Gender, Income, Number of Children, Number of Children with Autism, Time Since Diagnosis, Age of Child

Indicator	Estimated Loading (SE)	Standardized Loading	Residuals (SE)	R^2
ATEC Speech/Language/Communication:				
Parcel 1	2.14 (0.09)	0.96	0.52 (0.06)	0.92
Parcel 2	2.17 (0.09)	0.97	0.40 (0.06)	0.94
Parcel 3	1.96 (0.09)	0.92	0.88 (0.08)	0.85
ATEC Sociability:				
Parcel 1	2.49 (0.12)	0.87	2.03 (0.22)	0.76
Parcel 2	2.41 (0.12)	0.90	1.47 (0.19)	0.81
Parcel 3	1.96 (0.11)	0.83	1.83 (0.18)	0.69
ATEC Sensory/Cognitive Awareness:				
Parcel 1	2.56 (0.12)	0.90	1.68 (0.18)	0.81
Parcel 2	2.19 (0.11)	0.88	1.48 (0.15)	0.78
Parcel 3	2.37 (0.11)	0.91	1.27 (0.14)	0.83
ATEC Health/Physical/Behavior:				
Parcel 1	3.77 (0.20)	0.87	4.76 (0.61)	0.76
Parcel 2	3.31 (0.19)	0.81	6.09 (0.62)	0.65
Parcel 3	3.53 (0.20)	0.82	6.17 (0.65)	0.68
Snyder Hope Scale (HS-R2):				
Goals	5.74 (0.31)	0.82	16.14 (1.50)	0.68
Pathways	5.66 (0.29)	0.85	12.87 (1.31)	0.72
Agency	6.28 (0.28)	0.92	7.08 (1.16)	0.85

Parents' Hope for Their Child (PHC):				
Goals	4.82 (0.31)	0.73	21.55 (1.85)	0.53
Pathways	6.27 (0.32)	0.86	13.88 (1.64)	0.75
Agency	5.30 (0.26)	0.88	8.57 (1.09)	0.77
Kendall Chronic Sorrow Instrument (KCSI):				
Parcel 1	6.12 (0.26)	0.94	4.67 (0.72)	0.89
Parcel 2	5.04 (0.22)	0.92	5.00 (0.59)	0.84
Parcel 3	4.82 (0.23)	0.88	6.79 (0.64)	0.78
Family Quality of Life:				
Family Interaction	1.13 (0.09)	0.64	1.92 (0.16)	0.41
Parenting	1.41 (0.08)	0.83	0.95 (0.11)	0.68
Emotional Well-Being	1.63 (0.11)	0.73	2.40 (0.22)	0.53
Physical/Material Well-Being	1.04 (0.10)	0.56	2.44 (0.20)	0.31
Disability Related Support	1.81 (0.13)	0.70	3.60 (0.32)	0.49
MHI Depression:				
Item 1	0.70 (0.04)	0.84	0.20 (0.02)	0.71
Item 2	1.00 (0.05)	0.90	0.25 (0.03)	0.80
Item 3	0.87 (0.05)	0.77	0.51 (0.04)	0.60
Item 4	0.99 (0.05)	0.90	0.23 (0.03)	0.81
MHI Anxiety:				
Parcel 1	2.51 (0.12)	0.89	1.80 (0.20)	0.78
Parcel 2	2.50 (0.12)	0.87	2.02 (0.22)	0.76
Parcel 3	2.65 (0.13)	0.90	1.82 (0.22)	0.80

MHI Positive Affect:				
Parcel 1	3.78 (0.16)	0.94	1.91 (0.24)	0.88
Parcel 2	3.00 (0.13)	0.92	1.55 (0.17)	0.85
Parcel 3	2.99 (0.13)	0.92	1.66 (0.17)	0.85

of the variables in the current study. Total number of children had a significant effect on level of chronic sorrow, with parents with more children found to have less severe chronic sorrow than those with fewer children. Income was found to have significant negative effects on all of the autism severity measures. Age of child had a positive effect on autism severity in the speech/language/communication, and the sensory/cognitive awareness categories. This was expected as some of the items in these categories are affected by the developmental level of the child. Age of child was also found to have significant positive effects on parents' hope for their child and positive affect. Time since diagnosis had a significant positive effect on parents' hope for their child. Time since diagnosis also had significant positive effects on autism severity in the categories of speech/language/communication and sensory/cognitive awareness. This indicates that as time since diagnosis increases, the severity of symptoms in these areas will also tend to increase. While this might at first seem counter-intuitive, it is possibly an effect of certain questions on these subscales. A few questions ask parents to compare the functioning of the child with average functioning at this age and the tendency will be for the child with autism to be further behind peers as time passes.

As expected, several of these control variables had significant effects on the latent variables in the study. Also as expected, adding these control variables reduced the size of many

of the correlations. However, a few of the correlations between the autism severity variables and other variables increased in magnitude, with the previously non-significant correlation between satisfaction with support and autism severity in the speech/language/communication category becoming significant after adding the control variables. The correlations between anxiety and autism severity in the speech/language/communication, sociability, and sensory/cognitive awareness categories were the only correlations that changed from significant to non-significant when controlling for gender, income, number of children, number of children with autism, age of child with autism, and time since diagnosis. This shows that the relationships between hope and parents' hope for their child and autism severity, chronic sorrow, satisfaction with support, and mental health cannot be explained simply by a shared covariance due to gender, income, number of children, number of children with autism, age of child with autism, and time since diagnosis.

To provide information about how the hope and parents' hope for their child subscales were related to the different variables, a model was run with these subscales as latent variables. The authors of the HS-R2 scale have previously generated representative parcels for the subscales and these were also used in the current study and duplicated for the PHC subscales (Shorey, Little, Rand, & Snyder, 2005). Each parcel consisted of two items from the corresponding subscale. The correlations between the hope subscales, the parents' hope for their child subscales, and the other latent variables for this model are presented in Table 12. The loadings, residual variances, and squared multiple correlations for each of the indicators are presented in Table 13. This model had acceptable fit on all fit indices (χ^2 (975)=2018.404, p<.0001 , RMSEA=0.053 (90% CI = .050; .056), NNFI=0.914, CFI=0.925). Table 14 provides significance tests for the correlations between the subscales of hope and the other latent variables, and Table 15 provides significance tests for the correlations between the subscales of

Table 12. Correlations between Hope and Parents' Hope for Their Child Subscales and Latent Variables

	HS-R2 Goals	HS-R2 Pathways	HS-R2 Agency	PHC Goals	PHC Pathways	PHC Agency
HS-R2 Goals	1.00					
HS-R2 Pathways	0.848** (0.029)	1.00				
HS-R2 Agency	0.948** (0.022)	0.972** (0.022)	1.00			
PHC Goals	0.679** (0.042)	0.565** (0.051)	0.634** (0.046)	1.00		
PHC Pathways	0.540** (0.049)	0.675** (0.042)	0.602** (0.046)	0.789** (0.036)	1.00	
PHC Agency	0.601** (0.049)	0.657** (0.047)	0.759** (0.040)	0.864** (0.033)	0.956** (0.026)	1.00
ATEC Speech/Language/ Communication	-0.051 0.059	-0.147* (0.059)	-0.085 (0.060)	-0.182** (0.059)	-0.205** (0.058)	-0.180** (0.061)
ATEC Sociability	-0.183** (0.059)	-0.181** (0.060)	-0.162** (0.061)	-0.363** (0.057)	-0.386** (0.055)	-0.354** (0.058)
ATEC Sensory/ Cognitive Awareness	-0.180** (0.058)	-0.225** (0.059)	-0.164** (0.060)	-0.305** (0.057)	-0.321** (0.056)	-0.288** (0.060)
ATEC Health/ Physical/Behavior	-0.056 (0.062)	-0.082 (0.063)	-0.141* (0.062)	-0.223** (0.062)	-0.330** (0.058)	-0.233** (0.063)
Satisfaction with Support	0.413** (0.054)	0.477** (0.054)	0.536** (0.050)	0.436** (0.056)	0.665** (0.042)	0.575** (0.051)
Chronic Sorrow	-0.298** (0.055)	-0.368** (0.056)	-0.405** (0.054)	-0.247** (0.059)	-0.503** (0.047)	-0.411** (0.055)
Depression	-0.377** (0.053)	-0.401** (0.054)	-0.515** (0.049)	-0.194** (0.060)	-0.346** (0.055)	-0.279** (0.060)
Anxiety	-0.258** (0.056)	-0.386** (0.055)	-0.432* (0.053)	-0.238** (0.059)	-0.323** (0.056)	-0.256** (0.061)
Positive Affect	0.464** (0.048)	0.505** (0.049)	0.583** (0.044)	0.336** (0.056)	0.510** (0.047)	0.466** (0.052)

Standard error in parenthesis.
*Significant at $p<.05$
**Significant at $p<.01$

Table 13. Loading and Residuals for Each Indicator for Model with Hope and Parents' Hope for Their Child Subscales as Latent Variables

Indicator	Estimated Loading (SE)	Standardized Loading	Residuals (SE)	R^2
HS-R2 Goals:				
Parcel 1	2.02 (0.14)	0.71	3.96 (0.34)	0.51
Parcel 2	2.29 (0.12)	0.84	2.23 (0.24)	0.70
Parcel 3	2.09 (0.12)	0.80	2.47 (0.23)	0.64
HS-R2 Pathways:				
Parcel 1	1.77 (0.12)	0.71	3.13 (0.27)	0.50
Parcel 2	2.30 (0.13)	0.81	2.77 (0.28)	0.66
Parcel 3	1.97 (0.13)	0.74	3.16 (0.28)	0.55
HS-R2 Agency:				
Parcel 1	1.88 (0.11)	0.77	2.39 (0.21)	0.60
Parcel 2	1.73 (0.12)	0.70	3.07 (0.25)	0.49
Parcel 3	2.58 (0.14)	0.80	3.72 (0.32)	0.64
PHC Goals:				
Parcel 1	1.90 (0.15)	0.63	5.41 (0.46)	0.40
Parcel 2	1.96 (0.12)	0.77	2.66 (0.27)	0.59
Parcel 3	2.04 (0.13)	0.78	2.74 (0.28)	0.60
PHC Pathways:				
Parcel 1	2.05 (0.13)	0.74	3.59 (0.32)	0.54
Parcel 2	2.61 (0.15)	0.81	3.58 (0.35)	0.66
Parcel 3	2.07 (0.12)	0.79	2.61 (0.25)	0.62

PHC Agency:				
Parcel 1	1.99 (0.14)	0.69	4.31 (0.36)	0.48
Parcel 2	2.08 (0.13)	0.77	3.03 (0.29)	0.59
Parcel 3	1.31 (0.10)	0.68	2.00 (0.17)	0.46
ATEC Speech/Language/Communication:				
Parcel 1	2.38 (0.10)	0.96	0.52 (0.06)	0.92
Parcel 2	2.41 (0.10)	0.97	0.39 (0.06)	0.94
Parcel 3	2.18 (0.10)	0.92	0.89 (0.08)	0.84
ATEC Sociability:				
Parcel 1	2.57 (0.13)	0.88	2.02 (0.22)	0.77
Parcel 2	2.47 (0.12)	0.90	1.50 (0.19)	0.80
Parcel 3	2.02 (0.11)	0.83	1.82 (0.18)	0.69
ATEC Sensory/Cognitive Awareness:				
Parcel 1	2.66 (0.12)	0.90	1.70 (0.18)	0.81
Parcel 2	2.28 (0.11)	0.88	1.47 (0.15)	0.78
Parcel 3	2.47 (0.11)	0.91	1.26 (0.14)	0.83
ATEC Health/Physical/Behavior:				
Parcel 1	3.87 (0.20)	0.88	4.60 (0.61)	0.77
Parcel 2	3.37 (0.19)	0.80	6.19 (0.62)	0.65
Parcel 3	3.60 (0.20)	0.82	6.21 (0.64)	0.68
Kendall Chronic Sorrow Instrument (KCSI):				
Parcel 1	6.17 (0.26)	0.94	4.95 (0.74)	0.89
Parcel 2	5.12 (0.23)	0.92	4.79 (0.60)	0.85

Parcel 3	4.88 (0.23)	0.88	6.83 (0.65)	0.78
Family Quality of Life:				
Family Interaction	1.15 (0.09)	0.64	1.93 (0.16)	0.41
Parenting	1.45 (0.08)	0.83	0.94 (0.11)	0.69
Emotional Well-Being	1.66 (0.11)	0.73	2.42 (0.22)	0.53
Physical/Material Well-Being	1.07 (0.10)	0.57	2.42 (0.20)	0.32
Disability Related Support	1.83 (0.13)	0.69	3.65 (0.32)	0.48
MHI Depression:				
Item 1	0.71 (0.04)	0.85	0.20 (0.02)	0.72
Item 2	1.01 (0.05)	0.90	0.25 (0.03)	0.80
Item 3	0.88 (0.05)	0.77	0.51 (0.04)	0.60
Item 4	1.00 (0.05)	0.90	0.23 (0.03)	0.81
MHI Anxiety:				
Parcel 1	2.56 (0.12)	0.89	1.79 (0.20)	0.79
Parcel 2	2.56 (0.13)	0.88	1.99 (0.22)	0.77
Parcel 3	2.70 (0.13)	0.89	1.84 (0.22)	0.80
MHI Positive Affect:				
Parcel 1	3.82 (0.16)	0.94	1.90 (0.24)	0.89
Parcel 2	3.02 (0.13)	0.93	1.55 (0.17)	0.86
Parcel 3	3.01 (0.13)	0.92	1.68 (0.17)	0.84

Table 14.

Correlation Comparisons Hope Subscales							
	Goals	Pathways	Agency	Original Chi-Square	Constrained Chi-Square	Chi-Square Difference	*p*-value
Chronic Sorrow	-0.298	-0.368		988.232	989.334	1.102	ns
	-0.298		-0.405		993.770	4.538	<.05
		-0.368	-0.405		989.229	0.997	ns
Satisfaction with Support	0.413	0.477		988.232	989.127	0.895	ns
	0.413		0.536		994.460	6.228	<.05
		0.477	0.536		990.480	2.248	ns
ATEC Speech/ Language/ Communication	-0.051	-0.147		988.232	991.982	3.750	ns
	-0.051		-0.085		988.712	0.480	ns
		-0.147	-0.085		990.547	2.315	ns
ATEC Sociability	-0.183	-0.181		988.232	988.280	0.048	ns
	-0.183		-0.162		988.753	0.521	ns
		-0.181	-0.162		988.486	0.254	ns
ATEC Social/ Cognitive Awareness	-0.180	-0.225		988.232	988.569	0.337	ns
	-0.180		-0.164		988.763	0.531	ns
		-0.225	-0.164		990.316	2.084	ns
ATEC Health/ Physical/ Behaviors	-0.056	-0.082		988.232	988.399	0.167	ns
	-0.056		-0.141		991.160	2.928	ns
		-0.082	-0.141		989.985	1.753	ns
Depression	-0.377	-0.401		988.232	988.300	0.068	ns
	-0.377		-0.515		997.179	8.947	<.01
		-0.401	-0.515		996.282	8.050	<.01
Anxiety	-0.258	-0.386		988.232	994.190	5.958	<.05
	-0.258		-0.432		1003.693	15.461	<.001
		-0.386	-0.432		989.832	1.600	ns
Positive Affect	0.464	0.505		988.232	988.367	0.135	ns
	0.464		0.583		994.164	5.932	<.05
		0.505	0.583		992.752	4.520	<.05

Table 15.

Correlation Comparisons Parents' Hope for Their Child Subscales							
	Goals	Pathways	Agency	Original Chi-Square	Constrained Chi-Square	Chi-Square Difference	*p*-value
Chronic Sorrow	-0.247	-0.503		988.232	1019.124	30.892	<.001
	-0.247		-0.411		995.553	7.321	<.01
		-0.503	-0.411		1004.617	16.385	<.001
Satisfaction with Support	0.436	0.665		988.232	1019.801	31.569	<.001
	0.436		0.575		994.176	5.944	<.05
		0.665	0.575		1007.912	19.680	<.001
ATEC Speech/ Language/ Communication	-0.182	-0.205		988.232	988.601	0.369	ns
	-0.182		-0.180		988.794	0.562	ns
		-0.205	-0.180		990.851	2.619	ns
ATEC Sociability	-0.363	-0.386		988.232	989.647	1.415	ns
	-0.363		-0.354		988.811	0.579	ns
		-0.386	-0.354		993.919	5.687	<.05
ATEC Social/ Cognitive Awareness	-0.305	-0.321		988.232	989.102	0.870	ns
	-0.305		-0.288		989.072	0.847	ns
		-0.321	-0.288		993.215	4.983	<.05
ATEC Health/ Physical/ Behaviors	-0.223	-0.330		988.232	992.973	4.741	<.05
	-0.223		-0.233		988.290	0.058	ns
		-0.330	-0.233		997.740	9.508	<.01
Depression	-0.194	-0.346		988.232	1001.149	12.917	<.001
	-0.194		-0.279		990.823	2.591	ns
		-0.346	-0.279		996.122	7.890	<.01
Anxiety	-0.238	-0.323		988.232	993.330	5.098	<.05
	-0.238		-0.279		988.338	0.106	ns
		-0.323	-0.279		994.712	6.480	<.05
Positive Affect	0.336	0.510		988.232	1008.398	20.166	<.001
	0.336		0.466		993.608	5.376	<.05
		0.510	0.466		998.131	9.899	<.01

parents' hope for their child and the other latent variables. In the case of hope, agency had the strongest relationship with chronic sorrow, support, and the mental health variables, followed by pathways, and with goals having the weakest relationship with these variables, although most of the differences in the sizes of the correlations were non-significant. For parents' hope for their child pathways was found to have the strongest relationship with all of the non-hope variables, followed by agency, and with goals having the weakest relationship. The correlations between pathways and all of the other latent variables, except the autism severity variables, were found to be significantly stronger than the same relationships between the latent variables and the two other parents' hope for their child subscales. As would be expected the subscales for hope had highest correlations with the corresponding subscales for parents' hope for their child.

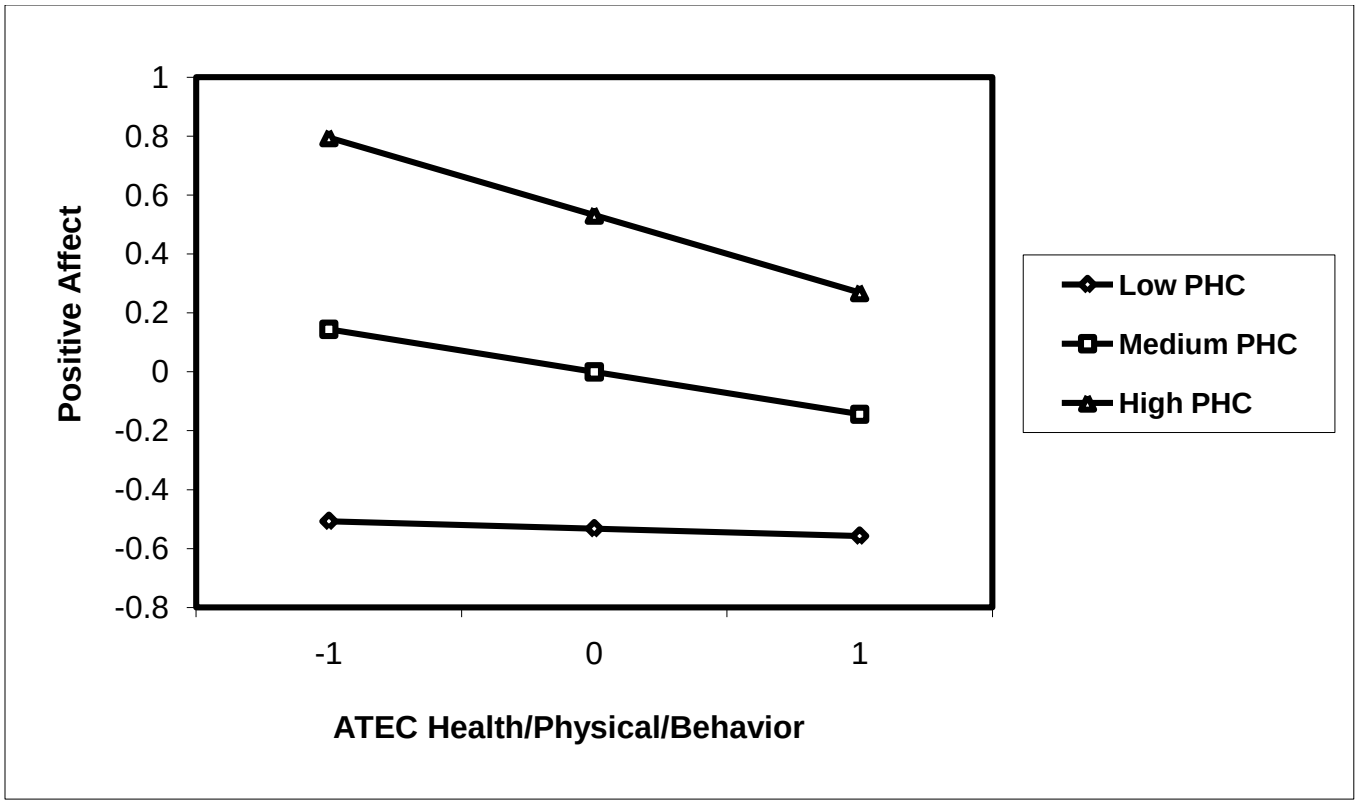
Interaction Models

It was hypothesized that hope and parents' hope for their child would moderate the effect of autism severity on mental health and chronic sorrow. As it had previously been found that the models worked better with the ATEC subscales and the mental health variables as separate latent variables, it was decided to run separate interaction models with all of the different possible interaction relationships. Of all of the different interaction models, only three interactions were found to be significant. Parents' hope for their child had a significant moderating effect on the relationship between autism severity in the area of sociability and positive affect ($p<.05$), on the relationship between autism severity in the area of sensory/cognitive awareness and positive affect ($p<.05$), and on the relationship between autism severity in the area of health/physical behavior and positive affect ($p<.05$). Contrary to the hypothesis, there was a stronger effect of increased autism severity on positive affect in parents with high hope for their child than for

parents with lower hope for their child. Graph 1 gives a visual presentation of the moderating effect of parent's hope for their child on the relationship between autism severity and positive

Graph 1.

Interaction Effect of Parents' Hope for Their Child on the Relationship between ATEC Health/Physical/Behavior and MHI Positive Affect



affect. The graph shows the impact of autism severity in the health/physical/behavior category at three different values of hope: the mean, one standard deviation above the mean, and one standard deviation below the mean. As can be seen from the graph, the slope is steeper for parents who have higher hope for their child than those with moderate level of hope for their child and those with low levels of hope for their child. However, since only three of the 32 interaction models were significant, any significant result is most likely due to chance.

All of the interaction models were also run with satisfaction with support, gender, income, number of children, number of children with autism, age of child, and time since diagnosis included as control variables. After controlling for the covariance of these variables, the only interaction effect to remain significant was the moderating effect of parents' hope for their child on the relationship between autism severity in the area of health/physical/behavior and positive affect ($p<.01$). Only one out of 32 interaction models reached significance, a result that could be expected simply based on chance. Therefore it can be concluded that hope and parent's hope for their child did not have a moderating effect on the relationship between autism severity and mental health factors in the present sample.

In summary, most of the main effects between hope and parents' hope for their child and the other variables were in the hypothesized directions. The majority of the hypothesized interactions of hope and parents' hope for their child on the relationship between autism severity and mental health factors and chronic sorrow were not found to be significant in the current study.

Discussion

The present study clarified the role of Snyder's (1994) construct of trait hope in the coping ability of parents of children with autism. The study also introduced the construct of a parent's specific hope related to their child and a new instrument to measure this construct. It was hypothesized that hope and parents' hope for their child would have a significant positive correlation. It was hypothesized that the two hope constructs would be positively correlated with satisfaction with support and positive affect, and negatively correlated with autism severity, chronic sorrow, depression, and anxiety. It was hypothesized that the correlation would be stronger between parents' hope for their child and the variables more directly related to the

functioning of the child (autism severity and chronic sorrow) than the correlation between these variables and overall hope. It was also hypothesized that hope and parents' hope for their child would have moderating effects on the relationships between autism severity and outcome variables such as chronic sorrow, depression, anxiety, and positive affect.

Internal Consistency and Validity of the Parents' Hope for Their Child Scale (PHC)

One of the goals of the current study was to address how parents' specific hope related to their child affects coping. A new scale was designed to measure the parents' hope for their child construct. The Parents' Hope for Their Child Scale (PHC) was based on the revised Snyder Hope Scale (HS-R2; Shorey et al., in press), an instrument that measures overall trait hope. The present study shows that the PHC has acceptable internal consistency and should represent a unidimensional variable.

The present study provided beginning evidence for the validity of the PHC. As expected, participants' scores on the PHC were highly correlated with their scores on the HS-R2 (.696). However, the overlap between the variables is low enough to indicate that they are distinct constructs. Campbell and Fiske (1959) suggested that correlation values below .85 after correction for the reduction in the correlation due to measurement error provide evidence for discriminant validity. The correlation between hope and parents' hope for their child was .769 after correcting for measurement error and suggests that the PHC has discriminant validity.

Parents' hope for their child was found to have significant negative correlations with variables that would be expected to have a negative relationship with this specific type of hope, such as the four measures of autism severity, chronic sorrow, depression, and anxiety. Parents' hope for their child was also found to have significant positive correlations with variables where this relationship would be expected, such as positive affect and satisfaction with support. More

importantly the PHC had significantly stronger relationships with variables more specifically related to the child, such as autism severity and satisfaction with support, than the relationships between these variables and general hope. Additionally, the correlations between hope and the general mental health variables, depression, anxiety, and positive affect, were stronger than the correlations between these variables and parents' hope for their child, although the difference was only significant for the correlations with depression. While it would be expected that general mental health would affect all and be affected by all aspects of hope, it is likely that these mental health factors will have a stronger effect on overall hope than on goal directed thinking related to their child.

In summary, the results in the present study indicate that the PHC is a reliable instrument and that it appears to have construct validity. Further research is needed to establish reliability of the measure over time and to investigate how the construct relates to other variables. It will also be important to test the instrument in a population of parents with children with no disorders. These parents face fewer struggles than parents of children with autism in achievement of goals they have for their children. It is therefore possible that there might be a higher correlation between hope and parents' hope for their child in this population than what was found for parents of children with autism.

The Effect of Autism Severity on Parents

Several changes were made to the proposed measurement model to obtain an acceptable fit. The main change was to split the autism severity variable into four separate variables based on the four different subscales of the ATEC. As mentioned above, the finding that autism symptoms in different areas do not necessarily go together fits with research on the Autism Spectrum Disorders showing that there are possibly several different subcategories of the

different disorders based on different clusters of symptoms (Volkmar & Klin, 2005). The ATEC divides autism symptoms into four separate categories: language/speech/communication, sociability, sensory/cognitive awareness, and health/physical/behavior. The last category constitutes many problem behaviors that are often seen in children with autism such as tantrums, self-injurious behaviors, and lack of toilet training.

The present study shows that the different categories of autism symptoms may have some distinct effects on the parents. Sociability, and sensory/cognitive awareness were the only autism severity categories that had significant correlations with hope, and they also had strong negative correlations with parents' hope for their child. Both of these categories are related to the child's interest and awareness of the surroundings, with sociability focusing on social aspects of the surroundings while sensory and cognitive awareness focuses on more general aspects of the surroundings. Severe symptoms in both of these areas could be expected to make it difficult for the parent to establish a close bond with the child, something which is likely to have a significant influence on agency towards goals related to the child. Many of the goals parents have for their children are focused on social aspects of life, and it is likely that impairments in this area would decrease hope and also make it difficult to envision new possible goals for the child. It is also often found that it is more complicated to design effective treatments for social skills and social awareness than for more concrete problems such as tantrums or a limited vocabulary (Handleman, Harris, & Martins, 2005). This would mean that it might be difficult for parents to create possible pathways towards goals in these areas.

As expected, all four categories of autism severity had a significant positive correlation with chronic sorrow. The correlations were especially strong between chronic sorrow and social/cognitive awareness and chronic sorrow and health/physical/behavior. Severe symptoms

in both of these areas would entail a larger caretaking burden for the parent as they encompass awareness of danger and self-help skills such as being potty trained and being able to dress oneself. Chronic sorrow has previously been found to be highly related to the unending caretaking role parents of children with disabilities are forced into (Burke et al., 1999). Similarly, it is not surprising that satisfaction with support was found to have a strong negative correlation with autism severity in the health/physical/behavior category. More support from family, friends and professional providers would be expected to have a positive effect on the behaviors of the child, possibly leading to a decrease in problem behaviors (Twoy et al., 2007). Additionally, it is likely that parents with children with fewer problem behaviors and better self help skills might feel less in need of support than parents of children with severe problem behaviors.

Severity of symptoms in the health/physical/behavior category was also found to have a strong relationship with the three mental health variables; depression, anxiety, and positive affect. As mentioned previously, problem behaviors, self-injurious behaviors, and lack of self help skills have been found to have a stronger negative effect on mental health in the parent than impairments in communication or social skills (Beck, Hastings, Daley, & Stevenson, 2004). Such behaviors add immense amounts of stress and unpredictability to the life of the family. The health/physical/behavior category also includes specific health problems such as seizures, sleep problems, and gastro-intestinal issues that can severely limit the life quality of the child and the family.

Income was found to have significant negative relationship with all of the autism severity categories. A possible hypothesis for this result is that parents with a higher income have access to more and better services for their child which in turn could lead to improvement in the child's condition. However, income was not significantly related to amount of hours of services

the child received. Additionally, amount of hours had positive correlations with two of the autism severity categories (speech/language/communication: r=.231, p<.001 ; sensory/cognitive awareness: r=.177, p<.001), showing that as the severity of the child's symptoms increases in these areas, so does the amount of help the family receives. This is an obvious relationship from the standpoint that as the severity of the disorder increases the need for and access to professional support increases. A more likely cause for the relationship between autism severity and income is that when the child has less severe symptoms, parents are able to work more. A child with severe symptoms requires a great investment of time and effort, and it has been found that many parents choose to stay home full time or reduce their work hours (Shearn & Todd, 1997). In the present study it was found that the speech/language/communication (r=.136, p<.05), the sociability (r=.105, p<.05), and the sensory/cognitive awareness (r=.165, p<.01) categories of autism severity were significantly correlated with the respondents' employment level, with fewer symptoms being related to more work hours.

Chronic Sorrow in Parents of Children with Autism

It was found that 83% of the participants in the sample scored in a range on the KCSI where chronic sorrow would be expected to be present. This illustrates how common it is for parents of children with autism to feel a sense of loss and sorrow. Participants also had significantly higher scores on measures of depression and anxiety than a college population. Having a child with autism adds high levels of stress to the lives of parents and also has a negative effect on their mental health (Hastings, 2003).

As hypothesized, chronic sorrow correlated positively with all of the categories of autism severity. Increased autism severity will usually entail more caretaking responsibilities, less emotional connection, and a larger gap between the actual child and the "expected" child (Roos,

2002). Chronic sorrow also correlated positively with depression and anxiety, and negatively with positive affect, hope, parents' hope for their child, and satisfaction with support. The correlation with depression was strong (r=.607), but not so strong that it would indicate identical constructs. An interesting finding was that chronic sorrow had a negative relationship with the number of children in the family. It is possible that having additional normal children reduces sorrow, because the parent in these cases has children that can reach expected developmental goals and milestones. Having normal children might help the parent focus on other aspects than the disorder in the midst of family and they can also be a source support.

Based on Copley and Bodesteiner's (1987) two phase theory of chronic sorrow, such sorrow would be experienced throughout the life of the parent, but usually becomes less intense with time as the parent moves into the second phase. Chronic sorrow did not have a significant relationship with time since diagnosis or age of the child in the current study. This indicates that chronic sorrow does not change with time, but rather remains at a constant level throughout the life of the child. This finding matches better with Olshansky's (1962) initial description of the sorrow reaction in parents of children with disabilities as a grief that continues at a significant level even years after the child is born.

Hope in Parents of Children with Autism

All of the direct relationships related to hope and parents' hope for their child were in the hypothesized direction. As predicted there was a strong positive correlation between hope and parents' hope for their child. However, the overlap between the two variables was not at a level suggestive of identical constructs. It is evident that goal attainment in important areas of a person's life will have a great effect on their overall level of hope. It is also likely that a person will have different levels of hope related to different areas of life dependent on the subjective

importance of the particular goals and previous success or failures in goal attainment (Snyder, 2002). An interesting aim for future hope research will be to find in what areas of life goal attainment or lack thereof will a have a stronger effect on overall hope.

As predicted, both hope and parents' hope for their child had significant associations with the measures of mental health. The hope factors correlated negatively with depression and anxiety, and correlated positively with positive affect. These results support previous findings showing that as hope increases mental health problems decrease, and with increasing hope the ability to experience positive affect also increases (Irving et al., 1990; Snyder et al., 1991). The important finding from the current study is that this relationship is significant also in parents of children with autism, a group that experiences a higher amount of stress than the average population.

Both hope and parents' hope for their child had a significant negative correlation with chronic sorrow, showing that as level of hope increases the severity of chronic sorrow decreases. This finding might indicate that people who are high in hope are less susceptible to develop chronic sorrow than those who are low in hope. This matches findings showing that people who are high in hope are less prone to develop mental health problems (Snyder et al.,1991). High hope has many advantages, for example the ability to reframe goals and find alternative goals, focus on positive aspects of life, and view problems as challenges, that would make high hopers better able to overcome sorrow after a loss than low hopers.

Since the study was not longitudinal and does not provide measures of how hope might change within each participant over time, it is difficult to say if parents experienced an initial depletion of hope with the manifestation of the first symptoms of autism or with the introduction of the autism diagnosis. Time since diagnosis was not found to have a significant effect on hope,

a result indicating that hope might remain fairly stable over time in this population despite the introduction of severe stressors in their life. It is possible that most of the participants had a reduction in hope immediately after the diagnosis was given and that they subsequently remained at this lower level of hope. However, the population in the present study had comparable hope values to that of a college population (Monsson, 2007). Although college students might not be representative of the normal population, previous studies have shown that college students have comparable hope levels to those found in the overall population (Bailey & Snyder, 2007). It can therefore be surmised that the participants in the present study most likely did not have a great change in their level of hope as a result of having a child with autism. Future studies should investigate hope levels and parents' hope for their child levels in parents of neurotypical children. This would provide a more appropriate comparison group for the population in the present study.

Time since diagnosis, did on the other hand, have a significant positive relationship with parents' hope for their child. This again provides evidence that hope and parents' hope for their child are distinct constructs, and that parents' hope for their child is more affected by variables directly related to the child than is the case with overall hope. Contrary to overall hope, parents' hope for their child does not remain stable with the time since diagnosis but rather tends to increase as time passes. There are several possible explanations for this result. It is likely that with time the parent becomes more used to having a child with autism and acquires a better understanding of what goals are possible for the child and how to reach these goals. The parent might also need some time to create new goals and to reframe the situation to be able to view the new reality in a more positive light. While it is possible that the increase in hope related to the child is a result of the healing power of time and a decrease in chronic sorrow and mental health

issues, this did not appear to be the case in the current study as time since diagnosis did not have a significant relationship with any of these variables.

Although overall hope was found to be significantly correlated with two categories of autism severity, the correlations were not strong. This indicates that overall hope remains fairly consistent even in the face of great hardship. Snyder (2000) hypothesized that goal attainment and losses throughout a person's life would affect level of hope. The results from the current study indicate that while the stressors of having a child with autism might have a significant effect on hope, the effect is not strong and hope level appears to remain fairly constant. However, there is an important caveat with the current results: it is possible that the participants in the present study have higher and more stable levels of hope than is found in the overall population of parents of children with autism. Participants are all active members of an autism group, they self selected for the study, and as there were no incentives other than learning more about coping in families with children with autism, they are likely to be motivated in general and also highly motivated about the autism cause. It is possible that people who did not respond and who are not members of an autism group are less motivated, have higher levels of chronic sorrow or mental health problems, and lower levels of hope. Future studies should attempt to recruit participants who are less active in autism support groups as it is possible that their results are significantly different than what was found in the current population.

Hope and parents' hope for their child were found to have strong positive correlations with satisfaction with support. It is likely that the availability of support has a positive influence on level of hope. It is also likely that people who are high in hope are more capable of utilizing support resources than more passive low hopers. People who are high in hope would be expected to be more proactive at creating support opportunities or asking for help. Although there are

many sources of support available for parents of children with autism, access to professional and other forms of help usually requires the parent to actively seek out these resources. Based on a conceptualization of high hopers as active in their goal pursuit, they would be expected to uncover more support sources and therefore be more satisfied with the support they receive (Snyder, 2002). Additionally, it has been found that people who are high in hope are more social and have better relationships with their family than people who are low in hope (Shorey et al., 2003). As friends and family constitutes important support sources, it would be expected that people who are high in hope would have more access to such support than those who are low in hope.

While a few previous studies have found an effect of gender on hope, with women having significantly higher hope than men, this was not found in the present study (Monsson, Shorey, & Seely, 2007). A possible explanation is that the fathers that responded to the questionnaire are more involved in their children's lives and more motivated for goals for their child and for goals in general than fathers who did not respond. As mentioned above, it is also likely that the participants in the present study are more motivated and have higher hope than what you would find in the overall population of parents of children with autism. None of the other descriptive variables, including income, number of children, ethnicity, or time since the diagnosis, had any significant effect on hope.

For the three subscales of the Snyder Hope Scale, the mean for the Agency subscale was significantly higher than the mean for pathways, with the Goals subscale having a significantly lower mean than the Pathways subscale. This pattern has been found in previous studies with the HS-R2 (Monsson, 2007, Shorey et al., in press). The results were quite different for the parents' hope for their child subscales where the mean for Pathways was found to be significantly lower

than the mean for the Agency and the Goals subscales. This indicates that while the parents are still very motivated to work towards the goals they have for their children and they still hold many goals for their children, they have difficulties envisioning ways to reach these goals. Many of the goals the parents had for their children will be out of reach due to the severe impairments caused by autism. While Snyder (2002) theorizes that high hope people in general might view such obstacles as challenges to overcome, it is likely that the obstacles for these parents are impossible to overcome. Even though parents might be skilled at creating new pathways in other areas of their life, this might not be possible when it comes to their child because of the effects of autism. However, the motivation and the goals might remain and it might even be viewed as a failure or betrayal of their child to give up on these goals. Due to the uncertainty about the causes of autism and the best treatment for people with autism, it might also be difficult for parents to have faith in the pathways they have selected.

In line with these assumptions, pathways was the element of parents' hope for their child that had the strongest relationship with all of the four categories of autism severity, chronic sorrow, and mental health issues. Additionally, pathways had the strongest positive correlation with satisfaction with support. It is likely that as the amount of support, both professional and otherwise, increases so will the parents expectation that they have available pathways to the goals they have for their child. There is also some good news: the pathways subscale of parents' hope for their child had a significant positive correlation with time since diagnosis (r=.124, p<.05). Consequently, it appears that pathways increase with time and possibly greater certainty about the abilities of the child and the child's future.

Moderating Effects of Hope

It was originally hypothesized that hope and parents' hope for their child would have moderating effects on the relationships between autism severity and mental health and chronic sorrow. As the autism severity variable had been divided into four different categories based on the ATEC subscales and the mental health variable had been divided into three separate categories, it was decided to run each possible interaction as a separate model to reduce the complexity of the models. Of the 32 different interaction models only three were significant: Parents' hope for their child moderated the effect of autism severity in the sociability category on positive affect, parents' hope for their child moderated the effect of autism severity in the category of sensory/cognitive awareness on positive affect, and parents' hope for their child moderated the effect of autism severity in the category of health/physical/behavior on positive affect. All three models had parents' hope for their child as the moderator variable and positive affect as the dependent variable. When controlling for the effect of satisfaction with support, gender, income, number of children, number of children with autism, the age of the child, and time since diagnosis, only the effect of parents' hope for their child on the relationship between the autism severity category of health/physical/behavior and positive affect remained significant. It would be expected just based on chance that one out of 32 models would yield a significant result.

Parents' hope for their child was found to have a moderating effect on the relationship between autism severity related to health/physical/behavior and positive affect. Contrary to the stated hypothesis, an increase in severity in health/physical/behavior had a stronger effect on positive affect in people with high hope for their child as compared to those with low levels of

hope for their child. However, as stated above, this result is most likely due to chance, since less than five percent of the interaction models were significant.

Based on these results, the hypotheses that hope and parents' hope for their child work as moderators on the relationship between autism severity and mental health problems and chronic sorrow were not supported. There are several possible reasons for these results. The correlations between autism severity and depression, anxiety, and positive affect were weak and in the case of depression mostly non-significant, and it is therefore likely that any effect of hope or parents' hope for their child would be non-significant. Regarding chronic sorrow, it is possible that an increase in severity of autism would affect parents to a similar degree regardless of the level of hope or hope for their child they might have. While parents who are high in hope or hope for their child might be more capable of turning to alternative goals or seeing positive aspects in the situation than someone with lower hope, it is possible that increasing disability will lead to the same sense of loss and sorrow. Most people experiencing chronic sorrow will go through periodic intense grief, and the severity of the child's symptoms appears to increase this grief regardless of a parent's level of hope. People who are higher in hope might have a lower level of chronic sorrow, depression, or anxiety and a higher level of positive affect in general than someone who is low in hope, but an increase in symptoms might affect parents at all levels of hope to the same degree.

It is also possible that interaction effects exist but that the study did not have enough power for these to reach significance. Interaction effects are by nature elusive and difficult to find. Future studies should attempt to collect data from a larger sample, and, as mentioned previously, a sample that includes parents not involved in autism groups, a population where hope levels might be lower.

Implications of Findings for Work with Families with Children with Autism

The present study provided additional evidence that parents of children with autism experience higher levels of mental health problems than the average population. Hope and parents' hope for their child were found to have significant negative correlations with chronic sorrow, depression, and anxiety, and significant positive relationships with positive affect. These results indicate that hope can be a beneficial factor in coping for parents of children with autism. High levels of hope are theorized to be related to many positive coping strategies and skills that can be used when dealing with the stress and grief of having a child with a severe disability.

With this in mind, focusing on increasing a parent's level of hope and helping them learn the skills and strategies that go along with high hope could potentially provide great advantages for these parents. Additionally, as the stressors they face especially influence the specific hope they have for their child, it could be particularly valuable to work on increasing parents' hope for their child. While increasing their ability to envision realistic goals and their motivation to work towards these goals of course would be beneficial, it appears that it is above all the pathways thinking that needs help. It is likely that many parents are overwhelmed and uncertain after receiving their child's diagnosis and that they might feel incapable of producing ways to reach the goals they have for their child. While the goals and the motivation to work towards the goals might remain, pathways thinking possibly deteriorates as they are unable to find routes to the goals and the routes they had envisioned are blocked.

So how can we help foster pathways thinking and in turn hope in this group of parents? One obvious solution would be to teach them about possible pathways towards the goals they might have for their child. As can be seen from the results in this study, many of these parents view themselves as just as capable of coming up with pathways for goals in other areas of their

life as college students. This should mean that it is not pathways thinking in general that is the problem but rather pathways related to their child. Unfortunately, researchers are still far away from agreeing of what causes autism and what treatments are most effective (Rapin, 2005). However, providing information and teaching parents to become better consumers of treatments could still be very beneficial. Studies have shown that the uncertainty about treatments for autism, research on autism, and causes for autism is a big stressor for many parents (Marcus et al., 2005). Parents have feelings of guilt because they believe they are not doing what is right or everything that is possible for the child. It is important that providers and professionals provide some of this information and that the information is available as soon as a diagnosis is made. While there are many things that are not known about autism, there is still much knowledge about the disorders. This information could help parents understand what the disorder entails, what they can expect from the future, and some possible ways of reaching the goals they might have for their child. More knowledge might help the parents eliminate or, at least, be less committed to goals that might be impossible to reach for a person with severe autism. This can in turn help parents find alternative goals, reframe their situation, and find more positive aspects in the achievements of their child. Helping parents with this can potentially raise their pathways thinking related to their child and the overall hope they have for their child.

Another important strategy to help the parents is to provide the needed professional support and also help them better access informal sources of support. Satisfaction with support was found to have a strong positive correlation with hope and parents' hope for their child. Ensuring that the parents receive the needed support is therefore essential for their hope and ability to cope with the stressors in their life. Moreover, as parents often feel that professionals are insensitive and do not understand them, it is important that professionals gain a better

understanding of the family and the sorrow they are struggling with (Knox et al., 2000). Better quality support might in many ways be just as important as the quantity of the support. An important aspect of the support could be to put parents in touch with other parents in the same situation, such as a parent support group, since peer support has been found to have a positive effect on coping (Smith, Oliver, & Innocenti, 2001; Twoy et al., 2007).

A program that helps parents with information and provides support from the time diagnosis is given or symptoms are first seen could be an important element in improving the lives of this population. It is likely that such efforts would help increase parents' hope and that it would reduce the severity of chronic sorrow, depression and anxiety. While helping these parents is an important goal in itself, this is also an essential goal from the viewpoint of the child with autism. It is evident that these children will have a more positive home atmosphere and possibly quality of life if their parents are more content and hopeful. Research has also shown that more positive parents and providers and a less stressful environment can lead to improvements in the child's functioning (Kuhn & Carter, 2006; Marcus et al., 2005). Such improvement could again lead to increased hope and positive affect in the parents. Focusing on increasing parents' levels of hope could in this way have important ripple effect throughout the lives of families of children with autism.

Limitations and Future Directions

Although the findings from the current study provide important information regarding coping and hope in parents of children with autism, there are several limitations. Because data were collected through the internet, it is possible that people from lower socio-economic groups were underrepresented. The median annual household income in the current sample was between seventy and eighty thousand dollars for the overall sample and between eighty and ninety

thousand dollars for married couples or couples living together. According to the US Census Bureau (2008) the median income in the overall population for the period between 2006 and 2008 was 52,175, with the median income for married-couple families at 74,732. As can be seen, the income in the current sample was higher than what is found in the general population and the current sample might therefore not be representative of the overall population. Since income was found to have a significant relationship with several variables, it is possible that the results would have been slightly different with a more representative sample.

Although most studies indicate that internet samples are representative of the general population, especially as use of computers has become extremely common, it is possible that it did present a limitation in other ways in the current study. Parents of children with more severe autism, or more stressors in general, are likely to have less time available to complete online surveys than parents with more support or children with less severe symptoms. This means that the current study might have missed many people with more severe stressors and therefore also more severe levels of mental health problems and chronic sorrow.

It is also possible that the sample is not representative of the overall population of parents of children with autism in other aspects. The current study sampled members of the Autism Society of America. It is likely that these parents are more active in the autism community and possibly in the community in general. Additionally, isolation and limited social engagement are common symptoms of depression, anxiety, and chronic sorrow. ASA provides support and information that can be beneficial for parents and help them with their coping. Considering these factors, it is likely that the members of ASA, and the participants in our sample, cope better and have lower levels of mental health problems than what might be found in a population of parents of children with autism who are not active in an autism support organization. A more

representative sample would likely have included more individuals with lower hope scores and higher scores on chronic sorrow, depression, and anxiety. It is probable that there would be a stronger negative relationship between hope and mental health problems in such a sample. It is also possible that some of the relationships that did not reach significance, such as potential moderating effects of hope on the relationship between autism severity and mental health factors, would be significant in a more representative sample. Future studies should attempt to sample parents who are not active in autism support organizations to investigate if the effects of autism severity on hope and mental health are stronger in these parents than what was found in the present sample. This is a group of parents that could potentially benefit even more from a support program.

Future studies should also compare the results of parents with children with autism with parents of normal children. The current study compared the hope scores and MHI scores with college students. College students are representative of the overall population in many ways and previous studies have found that hope levels in this group is comparable to hope levels in a normal population (Bailey & Snyder, 2007). However, much research has also shown that college students are different from the overall population on important traits and that results from college samples should not be readily generalized to other populations (Peterson, 2001; Sears, 1986). As a main factor in the coping of the participants in the current sample is these parents' relationship with their children, it is especially likely that college students, mostly with no children of their own, do not provide an appropriate comparison group.

It would be informative to perform a longitudinal study of how hope and mental health develop over time in parents of children with autism. Snyder (2000) hypothesized that people will usually experience a decrease in hope after a loss situation, such as receiving an autism

diagnosis, but that hope will slowly return to the previous level as time passes, at least in people with higher levels of hope. In the current study, time since diagnosis was used as an indicator of this change over time. This variable had a significant positive relationship with parents' hope for their child, but no significant effect on overall hope. However, time since diagnosis does not necessarily provide a good indicator of changes within each person. A longitudinal study measuring parents immediately after diagnosis is given and then at different times after the diagnosis, would provide a better picture of how hope, parents' hope for their child, chronic sorrow, and mental health change with time and development in the functioning of the child. This would provide vital information for designing the best possible support programs for parents, for example by indicating if different types of support and information might be more effective at different stages after the diagnosis.

Another potential limitation was the phrasing of the question related to the diagnosis of the child with autism. The question asked what diagnosis the child had. Since many children with an autism spectrum disorder might be diagnosed with different disorders at different stages in their life dependent on the available information, development, and general functioning at the time, it would have been more useful to get information on the most current diagnosis. For example, it is conceivable that a child diagnosed with Autistic Disorder at 18 months might rather be diagnosed with Asperger's Disorder or PDD-NOS a few years later with further development. Studies gathering information about current and previous diagnosis could provide important information about how such changes in diagnosis might affect coping in parents.

Additionally, a possible limitation of the study was the use of ATEC to measure autism severity. While the instrument has good correlation with other more formal ways of measuring autism symptom severity, it has a major disadvantage in that many of the questions are

confounded by the age of the child. For example, some of the items for the speech/language/communication category ask questions related to how many words the child is able to produce. Although it is not uncommon for children with autism, especially more severe cases, to remain non-verbal throughout their life, it is likely that some of the young children who were rated low on these questions will develop more language and that the results might be more a result of their age than symptoms of autism. In the present study, age of child was included as a control variable to attempt to correct this confound. The ATEC also includes items where the parent is asked to compare their child to normally functioning peers, but it is uncertain how accurate such a comparison could be. Future studies should use severity ratings by professional raters to ensure objectivity and more extensive knowledge about the development of normal children.

A problem with the ATEC, and possibly many other instruments used to measure autism, is the likelihood that the Autism Spectrum Disorders actually have many different subcategories with specific symptoms associated with them (Volkmar & Klin, 2005). It is possible that these different subcategories might have dissimilar effects on parents. Although this does not necessarily represent a problem for the current study, future studies should attempt to look at what specific symptoms and categories of symptoms might have the strongest effect on hope and mental health in parents. Again, with such specific knowledge it would be possible to design better support programs for the parents.

It will also be important for future studies to investigate what particular aspects of higher hope have the most beneficial effects on coping in parents of children with autism. As mentioned above, people who are high in hope are hypothesized to be better than those who are low in hope at problem solving, creating alternative goals, seeing positive aspects in situations, finding ways

to reach goals, reframing their current situation, and viewing obstacles as challenges. It is likely that most of the aspects of hope can have positive effects on coping; however, it could be useful for people supporting the parent to know what particular aspects have the most positive effects. Helpers could then put additional focus in these particular areas when working with parents of children with autism.

Conclusions

Although the present study provided no evidence that hope and the specific hope a parent has for their child work as buffers against the effects of increasing autism severity, it did show that hope and parents' hope for their child have strong direct relationships with depression, anxiety, positive affect, and chronic sorrow. While such a link has been established in a more general population before, it is important to note that it also exists in parents of children with autism, a population that lives with constant and severe stressors.

In the present study higher hope was related with lower levels of depression, anxiety, and chronic sorrow. High hope has many positive attributes such as ability to find alternative goals when current goals are blocked or impossible to reach, seeing the positive aspects of situations, reframing situations to find meaning even in difficult events, and good problem solving skills. These attributes can be especially important for parents of children with autism where every day can seem like a battle against insurmountable odds.

The present study also introduced the new concept parents' hope for their child and a new instrument to measure this. The new scale had good internal consistency and the study provided beginning evidence of the validity of the concept. Parents' hope for their child had significant relationships with autism severity, satisfaction with support, mental health variables, and chronic

sorrow. The concept and the instrument should be useful in studies of parents, both of normal children or children with disabilities or other difficulties.

Hope and parents' hope for their child can now be added to the list of factors that are beneficial for coping in parents of children with disabilities. A goal for the future will be to further investigate the effects of hope and specific aspects of hope on coping. These studies should inform the help that is provided to parents of children with autism. An important goal will be to design a support program that can help these families live happier and more hopeful lives.

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Appendix A

Information Statement

The Department of Psychology at the University of Kansas supports the practice of protection for human subjects participating in research. The following information is provided for you to decide whether you wish to participate in the present study. You should be aware that even if you agree to participate, you are free to withdraw at any time.

We are studying how parents of children with Autism Spectrum Disorders cope with having a child with a developmental disability. The questionnaire is expected to take no longer than 25 minutes to complete.

The content of the questionnaires should cause no more discomfort than you would experience in your everyday life. Although participation may not benefit you directly, we believe the information obtained from this study will help us identify factors that make it possible for parents to better handle the stressors they face due to their child's disorder.

Your participation is solicited, although strictly voluntary. Only a code number will identify the data we obtain. You will not be asked to provide your name or any identifying information. It is possible, however, with internet communications, that through intent or accident someone other than the intended recipient may see your response. If you would like additional information concerning this study before or after it is completed, please feel free to contact us by phone or mail. If you have any additional questions about your rights as a research participant, you may call (785) 864-7429 or write the Human Subjects Committee Lawrence Campus (HSCL), University of Kansas, 2385 Irving Hill Road, Lawrence, Kansas 66045-7563, email dhann@ku.edu.

Completion of the questionnaires indicates that you are at least 18 years old and are a willing participant in this study.

Sincerely,

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Appendix B

Demographic Questionnaire

Age:_____

Gender (circle one): Male Female

Ethnicity: (check one)

_____African American
_____Hispanic
_____White non-Hispanic
_____Asian/Pacific Islander (specify_____)
_____American Indian
_____Middle Eastern (specify_____)
_____Other (specify_____)

Highest grade or level completed in school (Please circle one).

8^{th}	10^{th}	12^{th}	Two-years of College	Bachelors Degree	Masters Degree	Doctoral Degree

Marital status (circle one):

Married Divorced Separated Single Domestic Partner

Employment status (self):
___ Full-time
___ Half-time
___ Part-time
___ Stay at home
___ On disability
___ Retired
___ Student

Employment (spouse/partner):
___ Full-time
___ Half-time
___ Part-time
___ Stay at home
___ On disability
___ Retired
___ Student

Annual household income: (Circle one; all numbers are in thousands of dollars)

Under 10 10-20 20-30 30-40 40-50 50-60 60-70 70-80 80-90 90-100

100-110 110-120 120-130 130-140 140-150 150-160 160-170 170-180 over 180

Number of children in household:

Gender:	Age:	Resides at home:	Autism Spectrum Disorder Diagnosis:
M/F	____	Y/N	Y/N
M/F	____	Y/N	Y/N
M/F	____	Y/N	Y/N
M/F	____	Y/N	Y/N
M/F	____	Y/N	Y/N
M/F	____	Y/N	Y/N

Other members living in the household (Check all that apply):

___ One grandparent
___ Two grandparents
___ Adult Siblings
___ Aunt/Uncle
___ Cousins
___ Friends'
___ Nanny/Caretaker
___ Other

The following questions are related to your child on the autism spectrum

Age of child:____ **Gender of child**: M/F

Diagnosis (check all that apply):

___ Autistic Disorder Severity level given at diagnosis:
___ Mild ___ Moderate ___ Severe ___Not given/uncertain
___ Asperger's Disorder
___ Pervasive Developmental Disorder Not Otherwise Specified
___ Rett's Disorder
___ Mental Retardation
___ Nonverbal Learning Disability
___ Attention-Deficit Hyperactivity Disorder
___ Sensory Integration Disorder
___ Tourette's syndrome
___ Obsessive Compulsive Disorder
___ Other, please specify:_____

Age when child was diagnosed:____

Diagnosed by (check all that apply):
___ Psychologist (Ph.D/Psy.D)
___ Psychiatrist (M.D.)
___ Pediatrician (M.D.)
___ Social Worker (L.C.S.W./M.S.W.)
___ School Psychologist
___ Other, please specify_____

Support services outside school hours (check all that apply):

Type:	Number of hours received:
___ Occupational Therapy	____
___ Applied Behavior Analysis	____
___ Music Therapy	____
___ Physical Therapy	____
___ Play Therapy	____
___ Speech Therapy	____
___ Counseling/Psychotherapy	____

Does he/she use any medications: Y/N
If Yes, please specify:_____

Appendix C

Autism Treatment Evaluation Checklist (ATEC)

Please circle the letters to indicate how true each phrase is:

I. Speech/Language/Communication: *[N] Not true [S] Somewhat true [V] Very true*

N S V 1. Knows own name
N S V 2. Responds to 'No' or 'Stop'
N S V 3. Can follow some commands
N S V 4. Can use one word at a time (No!, Eat, Water, etc.)
N S V 5. Can use 2 words at a time (Don't want, Go home)
N S V 6. Can use 3 words at a time (Want more milk)
N S V 7. Knows 10 or more words
N S V 8. Can use sentences with 4 or more words
N S V 9. Explains what he/she wants
N S V 10. Asks meaningful questions
N S V 11. Speech tends to be meaningful/ relevant
N S V 12. Often uses several successive sentences
N S V 13. Carries on fairly good conversation
N S V 14. Has normal ability to communicate for his/her age

II. Sociability: *[N] Not descriptive [S] Somewhat descriptive [V] Very descriptive*

N S V 1. Seems to be in a shell – you cannot reach him/her
N S V 2. Ignores other people
N S V 3. Pays little or no attention when addressed
N S V 4. Uncooperative and resistant
N S V 5. No eye contact
N S V 6. Prefers to be left alone
N S V 7. Shows no affection
N S V 8. Fails to greet parents
N S V 9. Avoids contact with others
N S V 10. Does not imitate
N S V 11. Dislikes being held/cuddled
N S V 12. Does not share or show
N S V 13. Does not wave 'bye bye'
N S V 14. Disagreeable/not compliant
N S V 15. Temper tantrums
N S V 16. Lacks friends/companions
N S V 17. Rarely smiles
N S V 18. Insensitive to other's feelings
N S V 19. Indifferent to being liked
N S V 20. Indifferent if parent(s) leave

III. Sensory/Cognitive Awareness: *[N] Not descriptive [S] Somewhat descriptive [V] Very descriptive*

N S V, 1. Responds to own name
N S V 2. Responds to praise
N S V 3. Looks at people and animals
N S V 4. Looks at pictures (and T.V.)
N S V 5. Does drawing, coloring, art
N S V 6. Plays with toys appropriately
N S V 7. Appropriate facial expression
N S V 8. Understands stories on T.V.
N S V 9. Understands explanations
N S V 10. Aware of environment
N S V 11. Aware of danger
N S V 12. Shows imagination
N S V 13. Initiates activities
N S V 14. Dresses self
N S V 15. Curious, interested
N S V 16. Venturesome - explores
N S V 17. "Tuned in" — Not spacey
N S V 18. Looks where others are looking

IV. Health/Physical/Behavior: *Use this code: [N] Not a Problem [MI] Minor Problem [MO] Moderate Problem [S] Serious Problem*

N MI MO S 1. Bed-wetting
N MI MO S 2. Wets pants/diapers
N MI MO S 3. Soils pants/diapers
N MI MO S 4. Diarrhea
N MI MO S 5. Constipation
N MI MO S 6. Sleep problems
N MI MO S 7. Eats too much/too little
N MI MO S 8. Extremely limited diet
N MI MO S 9. Hyperactive
N MI MO S 10. Lethargic
N MI MO S 11. Hits or injures self
N MI MO S 12. Hits or injures others
N MI MO S 13. Destructive
N MI MO S 14. Sound-sensitive
N MI MO S 15. Anxious/fearful
N MI MO S 16. Unhappy/crying
N MI MO S 17. Seizures
N MI MO S 18. Obsessive speech
N MI MO S 19. Rigid routines
N MI MO S 20. Shouts or screams
N MI MO S 21. Demands sameness
N MI MO S 22. Often agitated
N MI MO S 23. Not sensitive to pain
N MI MO S 24. "Hooked" or fixated on certain objects/topics
N MI MO S 25. Repetitive movements (stimming, rocking, etc.)

Appendix D

HS-R2

Directions: Read each item carefully. For each item, please select the option that best describes YOU and circle that option.

1. I have trouble getting what I want in life

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

2. I clearly define the goals that I pursue

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

3. I can think of many ways to get out of a jam

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

4. I have many goals that I am pursuing

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

5. I prefer easy goals over hard goals

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

6. I have what it takes to get the job done

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

7. I have difficulty finding ways to solve problems

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

8. I give up easily

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

9. I’m not good at coming up with solutions

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

10. I'm good at coming up with new ways to solve problems

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

11. I create alternate plans when blocked

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

12. I do not try hard enough to overcome challenges

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

13. I go after goals that are difficult and challenging

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

14. I do not care about the goals I am pursuing

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

15. It is difficult to find ways to get what I want

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

16. As long as I have a chance, I'll keep trying

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

17. I cannot come up with new goals

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

18. I'm not very motivated

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

Appendix E

Parents' Hope for Their Child Scale

Directions: Read each item carefully. For each item, please select the option that best describes how you work towards goals you have for your child with autism and circle that option.

1. I have trouble getting what I want for my child

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

2. I clearly define the goals I have for my child

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

3. I can think of many ways to solve problems faced by my child

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

4. I have many goals for my child

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

5. I prefer modest goals for my child over more challenging goals

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

6. I have what it takes to get my child through difficult times

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

7. I have difficulty finding ways to solve problems for my child

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

8. I give up easily when it comes to the goals I have set for my child

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

9. I'm not good at coming up with solutions for how to reach the goals I have for my child

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

10. I'm good at coming up with new ways to solve my child's life problems

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

11. I create alternate plans when I am not able to reach the goals I have set for my child

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

12. I do not try hard enough to overcome challenges related to my child

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

13. When it comes to my child, I go after goals that are difficult and challenging

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

14. I am not wholly committed to the goals I am pursuing for my child

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

15. It is difficult to find ways to get what I want for my child

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

16. As long as I have a chance, I'll keep trying to reach the goals I have for my child

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

17. I cannot come up with new goals to advance my child's life

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

18. I'm not motivated enough in pursuing the goals I have for my child

Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

Appendix F

MHI

These questions that follow are about how you feel, and how things have been with you mostly **WITHIN THE PAST MONTH.** For each question, please circle a number for the **ONE ANSWER** that comes **CLOSEST** to the way you have been feeling.

How often did you become nervous or jumpy when faced with excitement or unexpected situations during the past month?

1	2	3	4	5	6
Always	Very often	Fairly often	Sometimes	Almost never	Never

During the past month, how much of the time have you felt that the future looks hopeful and promising?

1	2	3	4	5	6
All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time

How much of the time, during the past month, has your daily life been full of things that were interesting to you?

1	2	3	4	5	6
All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time

How much of the time, during the past month, did you feel relaxed and free of tension?

1	2	3	4	5	6
All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time

During the past month, how much of the time have you generally enjoyed the things you do?

1	2	3	4	5	6
All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time

Did you feel depressed during the past month?

Yes, to the point that I did not care about anything for days at a time……	1
Yes, very depressed almost every day.....…….	2
Yes, quite depressed several times.....…….	3
Yes, a little depressed now and then.....……..	4
No, never felt depressed at all.....…….	5

How much of the time, during the past month, have you been a very nervous person?

1	2	3	4	5	6
All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time

When you got up in the morning, this past month, about how often did you expect to have an interesting day?

1	2	3	4	5	6
Always	Very often	Fairly often	Sometimes	Almost never	Never

During the past month, how much of the time have you felt tense or “high-strung”?

1	2	3	4	5	6
All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time

During the past month, how often did your hands shake when you tried to do something?

1	2	3	4	5	6
Always	Very often	Fairly often	Sometimes	Almost never	Never

How much of the time, during the past month, have you felt calm and peaceful?

1	2	3	4	5	6
All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time

How much of the time, during the past month, have you felt downhearted and blue?

1	2	3	4	5	6
All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time

How much have you been bothered by nervousness, or your "nerves," during the past month?

Extremely so, to the point where I could not take care of things.……....	1
Very much bothered.....	2
Bothered quite a bit by nerves.....	3
Bothered some, enough to notice.....	4
Bothered just a little by nerves.....	5
Not bothered at all by this.....	6

During the past month, how much of the time has living been a wonderful adventure for you?

1	2	3	4	5	6
All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time

During the past month, how much of the time have you felt restless, fidgety, or impatient?

1	2	3	4	5	6
All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time

During the past month, how much of the time have you been moody or brooded about things?

1	2	3	4	5	6
All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time

How much of the time, during the past month, have you felt cheerful, light-hearted?

1	2	3	4	5	6
All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time

During the past month, how often did you get rattled, upset, or flustered?

1	2	3	4	5	6
Always	Very often	Fairly often	Sometimes	Almost never	Never

During the past month, have you been anxious or worried?

	1
Yes, extremely so, to the point of being sick or almost sick.…	
Yes, very much so.....	2
Yes, quite a bit.....	3
Yes, some, enough to bother me.....	4
Yes, a little bit.....	5
No, not at all.....	6

During the past month, how much of the time were you a happy person?

1	2	3	4	5	6
All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time

How often during the past month did you find yourself having difficulty trying to calm down?

1	2	3	4	5	6
Always	Very often	Fairly often	Sometimes	Almost never	Never

During the past month, how much of the time have you been in low or very low spirits?

1	2	3	4	5	6
All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time

How often, during the past month, have you been waking up feeling fresh and rested?

Always, every day.....	1
Almost every day.....	2
Most days.....	3
Some days, but usually not.....	4
Hardly ever.....	5
Never wake up feeling rested.....	6

Appendix G

Kendall Chronic Sorrow Instrument

Please read the following statements carefully and choose the response that applies most closely to your own life and the loss you have felt as a result of your child's disorder and diagnosis.

		Almost Always	Frequently	Sometimes	Usually Not	Infrequently	Almost Never
1.	I think about the loss as if it had just happened						
2.	I feel saddened when I think of my child's disorder						
3.	I feel just as sad when I think of the disorder as I did when my child was first diagnosed						
4.	I feel like crying when something reminds me that my child has autism.						
5.	I feel full of sorrow.						
6.	I feel sadness when I am reminded that my child has autism						
7.	I feel saddened by things that other people see as unimportant or minor.						
8.	I feel full of sorrow when I think about what might or could have been if my child did not have autism.						
9.	I feel that the sadness related to my child's disorder comes and goes.						
10.	I feel that I have to give up things in my life because of my child's disorder.						
11.	I feel that I have control over my life situation.						
12.	I feel my life is not the same as I had hoped or dreamed it could be because of my child's disorder.						
13.	I think about what my life might have or could have been when I am reminded that my child has autism.						
14.	I feel alone during the times that I feel sadness related my child's disorder.						
15.	I feel that I have enough energy to deal with my life.						
16.	The changes in my life because of my child's disorder are unfair.						
17.	I believe that life is unfair.						
18.	I feel older than my age because of my child's disorder.						

Appendix H

Family Quality of Life Survey

The following questions are related to how you feel about your life together as a family. For these questions please consider your family as those people who think of themselves as part of your family and who support each other on a regular basis. Do not think about relatives (extended family) who are only involved in your family once in a while. Think about your family life over the past 12 months. We want to know how satisfied you are with the following things in your family. Please check the boxes that reflect your level of satisfaction with each item.

	How satisfied am I that…	Very Dissatisfied	Dissatisfied	Neither	Satisfied	Very Satisfied
1.	My family has the support we need to relieve stress.					
2.	My family members have friends or others who provide support.					
3.	My family members support each other to accomplish goals.					
4.	My family members show that they love and care for each other.					
5.	Adults in our family teach the children to make good decisions.					
6.	My family gets medical care when needed.					
7.	My family has a way to take care of our expenses.					
8.	Adults in my family have time to take care of the individual needs of every child.					
9.	My family member with a disability has support to accomplish goals at school or at workplace.					
10.	My family member with a disability has support to accomplish goals at home.					
11.	My family has good relationships with the service providers who provide services and support to our family member with a disability.					